

AMCHP Annual Conference, 2010

Moving Ahead Together:

Celebrating the Legacy, Shaping the Future of Maternal and Child Health

Shaping the Future of SIDS/SUID Programs

March 6-10, 2010

MODERATOR: So first we have Mary Adkins. She is the project director for the National SUID Center, Project IMPACT. Mary is the immediate past president of the Association of SIDS and Infant Mortality Programs, also known as ASIP. She has extensive experience in program development, individual and family group support, project management, developing health education curricula and convening and implementing community initiatives. Recent community and public health initiatives include the Infant Safe Sleep workshops and coalitions, Hospital Infant Safe Sleep Project, State and local FIMR and child death review teams. Ms. Adkins has over 25 years of public health nursing experience and has worked with Tomorrow's Child, Michigan SIDS from 1998 to present. She serves as the statewide program director for Michigan responsible for program development, training, resource materials and evaluation for statewide services related to prevention of infant death and group support for families who have experienced infant death. Target audience includes professionals, families and communities. She is a member of various infant mortality committees and initiatives and is a frequent speaker at state and national meetings. And Mary is right here. Here is Mary.

Annette Phelps, who is actually right down here, is the director of the Division of Family Health Services at the Florida Department of Health. She has worked in a variety of healthcare settings including a county health department, a college health service and acute care teaching hospitals. And advance registered nurse practitioner with a Master's of Science in nursing from the University of Florida, her program experience spans 30 years and is focused on maternal and child health issues ranging from school health to Healthy Start to kids care. Ms. Phelps was instrumental in the development of Florida's FIMR review and pregnancy associated mortality review processes. In addition, she has served on the advisory group for the development of the state Healthy Start Program and many other parent and child initiatives at the state level. Active at state and national levels in the MCH organizations she currently serves on the board of AMCHP where I work and the NFIMR consortium and has served as a faculty for and assisted in planning for the NFIMR conferences. Her programs accomplishments have been acknowledged with awards from the Florida Public Health Association MCH section and the Region Four MCH. Ms. Phelps completed participation in the National Public Health Leadership Institute Scholar Program in 2004.

Lena Camperlengo has been working with the SUID initiative at CDC since December 2007. During that time she has taken a leadership role in developing and implementing the SUID case registry. Lena is also completing her doctorate of public health at Florida A&M University. Previously she served as a nursing consultant and Florida's Medical Home champion with Florida's Department of Health.

Next we have Hanan Kallash. She has diverse public health background with over 15 years of public health education and training experience. For the past 6 years Ms. Kallash has been conducting trainings in SIDS risk reduction and bereavement support sensitivity workshops across the nation representing the National SIDS and the Infant Death Program Support Center and First Candle SIDS Alliance. She has trained over 2,000 nurses and Allied Healthcare professionals and attended 42 national and regional conferences.

And last, but not least, we have Shannon Stotenbur-Wing. She has been the program director for CAH, which contains the CDR program, for three years. Shannon has 15 years of experience in project and program management both at MPHI, which is Michigan Public Health Institute, and the Michigan Department of Human Services in the area of policy, practice and reform. She has extensive experience in recommendation and policy development as well as facilitating meetings with the department policymakers in order to direct change. Shannon has been asked to sit on the State of Michigan Child Welfare Reform Taskforce, which has been brought together to insure that policies and procedures are working together for the betterment of Michigan families. Shannon has also done work with CDC in the area of child maltreatment mortality surveillance.

So as you can see folks, we have an extensive panel here to speak with you today, so let's welcome Mary Lena, Hanan and Shannon today to speak with you. And as you can see we're trying to get our laptops together. So welcome.

Lena Camperlengo: Okay, third laptop is a charm. and So the way we're going to do this presentation this morning. We're being recorded, right? This afternoon. This evening. Let me get oriented to time here. The way we're going to do this, this afternoon is I will share the stage with Shannon. I'm going to talk about the SUID case registry from the CDC perspective and Shannon will talk about it from the state perspective. Then Hanan will talk from First Candle and then Mary and Annette will speak. They'll finish up, so that's sort of our itinerary for the next hour or so. Thank you for hanging in there. We know it's the end of the day. You're tired and all of that and we are going to get you up and moving around a bit, so if you thought you could sleep through this maybe you need to find another session. All right and thanks for hanging in there for the IT kind of glitches.

My name is Lena Camperlengo. Thanks so much for coming to this session. It's a topic that is near and dear to many of our hearts. We're talking about sudden, unexpected infant death and I'm going to be talking about the case registry that we've gotten started at the Centers for Disease Control and Prevention. I'm going to quickly talk about definitions, a bit of background for the case registry, tell you specifically what our case registry objectives are about and then talk a bit about the pilot program we have going on of which Shannon has one of the five states.

When we talk about SUID at the CDC we sort of agreed upon this term and the terminology it stands for sudden, unexpected infant death, so it really gets to those deaths that happen suddenly and unexpectedly, but whose manner and cause is not immediately obvious, so let's say an infant dies in a motor vehicle accident. You might say well that's sudden and unexpected, but the cause and manner of death is a little obvious, so we're talking about those deaths where you really have to do some investigation. They're typically referred to medical examiners or coroners for case investigation.

SIDS on the other hand, while the most common form of SUID and the ICD-10 code is R95, has historically been defined as the sudden death of an infant after three things occur. The first one is a complete autopsy. The second is an examination of the death scene and the third is a review of medical records, so those three things need to have occurred and basically with no findings, so autopsy no findings, exam of the death scene we still can tell what it is. We looked at the child's medical record. We still can tell what it is. Then you can call it SIDS.

Other common forms of SUID include ASSB, which is shorthand for accidental suffocation and strangulation in bed. That's the ICD-10 code W75 and perhaps you had heard some of the research came out of CDC recently that said that those rates have quadrupled in the last couple of decades. And then finally, cause unknown and this is hard to distinguish from SIDS. Remember, SIDS you got to have those three

things, we don't know, autopsy. We don't know after autopsy. We don't know after death scene. We don't know after looking at medical records, so cause unknown and SIDS kind of difficult to distinguish. This schematic just basically highlights those three forms of SUID as three of the most typical, but we do want to acknowledge that there are other forms of SUID. Let's say perhaps some of your death reviews have picked up overdose on cough medicine, on over the counter cough meds, that's sudden, unexpected. I can only be determined upon toxicology and autopsy, so that might be one case of SUID.

We like to further define SUID into explained versus unexplained SUID and this is sort of the list that we have going on here. The poisonings, head injuries, that means after we did this thorough case investigation or found something on autopsy, we found the reason why this baby died. That's and explained SUID. Unexplained SUID continues to be SIDS, cause unknown. And then these we can't rule out is it suffocation in bed or was it SIDS. We don't have good information. We can't rule either out.

So some of the background on why we look at SUID just to kind of put it in a public health framework. SUID mortality to sudden unexpected infant death is about 4,000 infants a year. More than half of those are attributed to SIDS currently and SIDS is, remains one of the... the leading cause of post neonatal mortality, that's from month one of month... the end of 12 months. It's the third leading cause of all infant mortality behind preterm and birth defects and as I spoke before, accidental suffocation and strangulation in bed rates have been increasing and we really like to frame this as

preventable infant mortality. I mean how hard have we tried collectively to keep pushing down those deaths due to preterm and pushing down the rates on birth defects and we really hit sort of a glass floor instead of a glass ceiling, but here we really have examined how can we get these rates further down.

Let's take a look at the rates. Let me orient you to the slide. The yellow line is SIDS, is SIDS rate over the years. The blue line is a combination of the other two SUID rates, that's accidental suffocation, strangulation in bed mixed with a cause unknown and then the green line because yellow and blue make green, that's a combination of both of those yellow and blue. So as you can see flat line on these ASSB, cause unknown through the early '90s and somewhere around 1995 or '97 we have a change going on and let's talk about the SIDS rate. When did Back to Sleep come out? About '94. '92 the AAP recommendation, 1994 Back to Sleep Campaign began and look at the steady decline afterwards and then we hit about '97 and things start to change. What we see is sort of the green line being the combination of all those causes of death has started to level out. While SIDS continues to decrease the blue line is starting to meet it, so we're seeing an offset of deaths due to SIDS are decreasing, yet death due to other causes is increasing. So we thought we should do this case registry so we can find out why these babies are dying and first we have to answer the question what is wrong with the system we have. The system we have in order to monitor these deaths is monitoring death certificates and they're fine for the ICD-10 codes and understanding you know what the trend is in these deaths, but they don't describe the context in which these infants died. You're not going to see a

description of the death scene in a death certificate. They're fine for the demographics and all that other good stuff we get from death certificates. We also don't know what the certifier's intendedness was. Did they intend when they wrote in that square, did they intend this to be a SIDS death or did they write when they said...? I've actually seen some written in there, "Well some people given the same circumstances might call this SIDS." Okay, so what are you calling it? So what was their intendedness?

And then discrepancy between death certifiers, while one medical examiner or coroner might call it SIDS another one clearly would not, so there is a lot of reasons why we don't want to look at death certificates as our cause or as our monitoring and looking at trends. And here is another reason. When they do finally put some terms down on their death certificate all of these terms will be coded as SIDS. Look at the last bullet.

When I did training for death scene investigation for infants I met a medical examiner who thought she was doing the best job by writing not SIDS on her death certificates, but the problem with the death certificates is it's the algorithm the coding algorithm is done by computers. The computer looks for keywords like SIDS. The word not in front of it doesn't register, so all of these terms if you're death certifier thinks they're doing a good job by calling it SUID, which I highlighted, which is a new term, which means something different wherever you go, instead of calling it SIDS it doesn't matter. It's getting counted as a SIDS death anyway.

So I tried to draw up a schematic because I think very visually and the red box is SUID and what I try to explain to people is that there is great research being done to understand how we get there on the genetics, on the environmental, on the behavioral factors. A lot of people are doing a lot of research to figure out what puts a baby more at risk. At the CDC we take it from the death and we're moving forward, so we're looking at the systems that influence SUID and who codes what for what after the death occurs and each of these boxes represents basically a system. The top box is sort of the best case scenario and the bottom is sort of the worst case scenario, so the death scene could have a whole complete reporting form filled out. There could be doll reenactments and photos or nothing could be done, then when it gets to the medical examiner or coroner or pathologist a complete autopsy if they have the resources. A visual autopsy means the baby died. It looks like an infant. Let's call it SIDS.

Then when it gets to the death certificate as I already mentioned it depends what the wording was on the death certificate and it depends on whether it was miss worded or miscoded based on what was there and then it gets to National Center for Health Statistics where it finally becomes a statistic and then that leads to what we know about SUID. We figured there was a lot of things we didn't know about SUID that we wanted to know this system was not telling us, so we got together and we said how about let's look at a case registry for sudden unexpected infant death? We revised the reporting form in '96. 1996 was the first one. In 2006 was a revised one. There

were workgroups put together to try and train people how to use this reporting form for death scene information collection at the death scene of an infant.

Then we did the training academies. We did a feasibility study with seven states to see is it even possible to do a SUID case registry. Do people even want it? And we heard, "Yes, yes, we do." "We can do this." And the suggestion was to build upon child death review. We had an information gathering session in 2008 and our partners basically told us this is what we need in the model. This is how it needs to go. These are what our objectives should be and this is how we should do it, so we listened to what our partners said we should do and we listened to what our partners said and these are the questions we would like to ask of a case registry.

And this is sort of conceptually how we see the case registry. It encompasses information from the scene, from the pathologist, from the coroner or medical examiner as well as the death review, the child death review. All of this encompasses what the SUID case registry would look like at CDC. So when we started it our objectives included three basic things. I really like to break it down very simply and we looked at individual based variables. In other words, was the child sick three days before? Was the child...? Did the child have immunizations? Was the child found underneath an adult? Was there soft bedding there? So these are individual based variables based on that child. Then something new, we collected system based variables. What was done at the autopsy? What was done at the death scene? Forget about the results, were they positive or negative. What tests were done and

what procedures were followed for this infant's death, so that we can improve the system of investigation?

And lastly we said based on all the confusion over looking at death certificates to try and figure out trends we should categorize deaths not based on the death certificate, but based on these two individual based variables plus the system based variables. So as I mentioned, they're partner driven. Partners wanted to know was there a fan on in the room? Was there a pacifier being used? Was the baby breastfed? And we integrated these new variables into the current child death reviews case reporting system and we called it version 2.1S for SUID and we included questions on maternal health, infant health, the sleep environment as well as test results from the autopsy. The system based variables were really measuring quality of the system. They were also integrated into the same case report and they included things that I mentioned before. What information did the medical examiner have before they conducted the autopsy and what tests and exams were performed during that autopsy?

And lastly, as I mentioned, the categorization, I think what is interesting about it is it mixes these systems with individual based variables and it also includes a mechanism for suffocation, so we're really looking at how can we use all of this information to best understand how this infant died.

The pilot program was funded... We funded five states starting in August of 2009. They came to CDC in October to be trained and we're going to do a short exercise

that we did during their training. Then the states went back and trained their own local child death review teams and their state based child death review teams. January 2010 we went live. January 4, 2010 we went live with data collection. Their first quarterly report is due in April and in September we're bringing the whole group back together again in Atlanta to talk about some of their challenges and how to overcome those challenges and to celebrate some of the successes. Our five states include Colorado, Michigan, Georgia, New Jersey and New Mexico.

Our SUID initiative at the CDC includes my colleagues Kerry Shapiro-Mendoza, Shin Kim, Monica Murphy, Terry Jerogi and Brianna Lozano and with that I will pass the baton over to Shannon to give you a state's perspective.

SHANNON STOTENBUR-WING: Thank you. I am the state director for Child Death Review in Michigan and we were as Lena said, really fortunate to be funded for this SUID case registry. We currently are statewide. We have 83 counties in Michigan and we have teams in all 83 counties in Michigan. I didn't do the full PowerPoint presentation. There is a lot of us here, so I'm just going to give kind of a synopsis. I'll be available to stay after if anybody wants to talk about any specific questions, but I just want to kind of talk to you about the impacts it has on states and really looking at the differential diagnosis or looking at something different than automatically talking about SIDS. And from a more practical standpoint a lot of what Lena talked about from the CDC, their objectives and here is what it's... here is all these different things we could do. From a state perspective and from those of you that are working sort of

at the ground level it's tough to shift this change. It's tough to get medical examiners especially to say that there is other alternatives other than well this baby died and we just don't know why. There is not glaring medical reason why these children died.

In Michigan we are very active in child death review and we review about 700 of our cases on average. 120 of those on average are these sudden, unexplained infant deaths under one, so those are the cases that we're taking a look at in more depth and really including these extra variables and Lena is very nicely... say there is a few extra variables. There is 200 extra variables, so for those of us in the field and you can imagine that looking at these cases in depth is hard enough, but now also going that next step and saying we're going to ask things like smoking, how many packs of cigarettes did you smoke, not just if there are... if you smoked while you were pregnant, if you smoked in the house, if other folks smoke in the house, but how many packs a day did you smoke, was the baby sick 72 hours prior to the event, so things like that and as you can imagine it puts a strain on professionals. It puts a strain on other folks, but what we've really tried to do is really talk about the benefits of knowing.

And in Michigan what we've seen over the years is a really significant decline in the cases being called SIDS. We've seen unfortunately lots of undetermined, which really doesn't get us any further and again we talk about this unknown as opposed to SIDS. What is that? You know how do you really differentiate that? And that is a good question. What we've really had to do is take a look at the cases and really talk to the medical examiners, the people doing the death scene reenactments. Training, we

now in Michigan train on average at least one a month, a death scene investigation training where we're pulling CPS working. We're pulling medical examiner, investigators and law enforcement into these where they're not normally comfortable. I always like to say when I do these trainings in front of law enforcement, law enforcement they don't like when babies die. They just don't like to deal with when babies die, so we really have to think about where are the limitations and where is the trepidation when they're doing these investigations. We want to make sure that they're asking these questions. Certainly they're not going to sit down with 230 extra variables on top of the... You know in Michigan we do... We have the sudden, unexplained infant death investigation form. It's comprehensive, but what we're trying to explain to them is getting a better picture of what is going on in these deaths are going... it's going to better enable us to make changes at the state level and vital stats, to make changes at the local level and partner with those folks doing this work. What happens when you make good... when you do these good investigations and get good information, we drive prevention initiatives and that's why we're all sitting in this room to try to figure out ways to not have these happen, to not have to go to these deaths.

A lot of what we do too is figure out ways that we can most accurately look at some of these variables and remind them that doing these death scene investigations are imperative to what we need to do as a whole. I'm not sure how much time I have, but a lot of what we talk about when we do death scene investigations, we are very lucky in most of our counties that we have somebody designated to do scene reenactments.

In the Detroit area, which obviously has... we have a high number of deaths. We have somebody dedicated that's on my staff that does death scene reenactments. She goes out on every single baby case and does a full reenactment and it's really we laugh about it and we get this information. It's unbelievable what some of these folks will tell her and it's unbelievable that people when she goes up and trains and says you know what, we take this baby, we do doll reenactments on every time. You know it's not pie in the sky. It's not something that can't be done. We just have to really take the initiative and know that we're getting information. We're getting variables that help us drive that prevention side.

Now we are in the very initial stages of looking at this pilot. We've been doing this work outside of what the CDC is asking on top of what the CDC is asking us to do for quite awhile and working in Michigan to really talk with those medical examiners that are still calling deaths SIDS and their neighbors, their neighbor medical examiner right down the street is calling it sudden unexpected or calling it accidental suffocation, so we are really working with them to really talk about what do you have before the autopsy, what do you have that's driving your determination. One of the things we hope to get out of this and what we're hoping that you can get out of a panel similar to this is you know do we need to make recommendations to our medical examiners about a protocol? And we're hoping that that comes out of... From the state level we're hoping that comes out of the three-year CDC project that we can talk with medical examiners and say here are the things that should be standard every time you have one of these deaths. If all else fails then we can call it this, so sort of a matrix of

okay, do we know we've done all this stuff and you have all this information and then you can call this case and we really tried to do that a lot in Michigan before the CDC project and certainly now that we have the CDC project.

We've really talked to local law enforcement too about asking for medical information, asking those questions about you know prior baby deaths. Those are questions... I'm sorry. I thought I saw a hand, okay. And for the first time unfortunately this year we've had in one of our areas our third baby death of the same family, the same mom and I have to tell you when the scene person comes to your door and you are the mom and you say, "Oh, I remember you." That has to be telling us as a system we're not getting the message across and that is why I was really happy when Lena asked me to present from a state perspective. I really wanted to give you the local take on this, that it is important all the way around. It is important at the local level and it's important to that mom because she is going to have another baby and we need to make sure that we get away from this. And she said to her, "Well my last two babies dies of SIDS, so I'm not surprised that this one did too." Well she was bed sharing with all three of them and it never was... It never got through. The message didn't get through to her and we don't really know why that is. There are resources in place that should have gotten the message through, but it didn't and so what can we do when we find out this information in three years? When we have the information tabulated, when we look at the variables, what are we going to do about it and what can we do as system, as a prevention system, as an investigatory system, as a medical examiner

system to insure that we're getting the information across that's going to help drive prevention that works?

So in Michigan we don't have... We average 120 cases a year. As of the second week in February we had 25. That's frightening. It's frightening for us and I'm sure I see faces wincing out there. It's in your backyard too and we've got to do a better job at looking at what exactly is happening and making sure that we're not just putting it into the batch of oh, I don't know. We really need to make sure we're giving medical examiners and coroners all the information they need to make good cause and manner determinations. So with that I'll let you go to the next exercise.

Lena Camperlengo: How many of you participate in either a FIMR or a child death review team? All right, then this shouldn't be such a difficult experience for you. What we want to do is sort of illustrate how difficult it is sometimes based on limited information, which is what you get, a Child Death Review, which is what medical examiners get and we want you to read through the scenario and then you're going to pick a corner. We have if you think this baby died of cause unknown, if you think this baby died of SIDS, if you think this baby died of SUID or accidental suffocation and strangulation in bed you will go to those corners.

Basically let me read it out loud quickly. This three month-old was found alive when she woke up to breastfeed. Mom and her had been asleep in the same bed since 11:00 that night. After breastfeeding, the mom placed the baby on her back to sleep

with a pacifier in her mouth on an adult queen size mattress between her and her husband at about 3:20am.

Jane's father woke up at 6:30am to discover Jane unresponsive. The parents attempted CPR, called 911. Paramedics arrived in 12 minutes, also attempted CPR. Paramedics transported Jane to the local hospital where she was pronounced dead. Parents report Jane was found by her father on her back between her mother and her father and she had been a healthy baby, never had been sick. A fitted sheet was secured to the bed. A light sheet was used for covers, so there was no blankets. An operating ceiling fan and an open window provided ventilation in the apartment that was not air conditioned. Room temperature was about 70 degrees. Parents report Jane typically sleeps between them on the queen sized mattress and that they always place her to sleep on her back. Neither parent reports smoking. The bedroom appeared neat and clean. The review of the medical records showed no relevant medical history and basically the autopsy results were negative. So based on the information you have go find a corner.

Now remember what is the definition of SIDS? It's negative after scene, the death scene. It's negative after autopsy and negative after medical record review, so if all those are negative what are you supposed to call it? You're supposed to call it SIDS. If all of those are negative you're supposed to call it SIDS, so cause unknown we argued often that a cause unknown in an infant is SIDS by definition and when we did this recently with coroners in Georgia everybody from over here walked on over here

and then people started switching around. I can't believe we don't have a SUID. Well let's say there was somebody standing there. What would that death be called once it hits the vital statistics?

Audience: SIDS.

Lena Camperlengo: It would be called SIDS, so everybody from that corner would be standing over here anyway. So we really have two corners going on when you really break it down. All right ASSB folks, you're the crowd. Based on what evidence did you call it ASSB?

Audience: Gut reaction.

Lena Camperlengo: Gut reaction and sometimes that is what death certifiers use. They were taught... This is what they were trained to do and that's why they choose one diagnosis versus the other, but given the same information this room was split, which is why the case registry is attempting not to use what the death certificate says and not to use what one trained medical examiner says versus another trained medical examiner, but using all the information on those individual based variables and what tests were done to be able to categorize how these infants died. Does that make sense? Any information that this group would like that might put you in a different group? Is there any autopsy results that confirm this baby was suffocated?

Audience: No.

Lena Camperlengo: There isn't. There is no autopsy result that would confirm a baby in this corner versus here.

Audience: Are there any autopsy results that ever would confirm?

Lena Camperlengo: Well I have heard some tests say that there was an expression of certain proteins that come out when a baby is suffocated and if you can measure those proteins that maybe you can make a case that the baby died of suffocation versus whatever else it might be.

Audience: **** you have actually cleared you know blanching or you know there are some definite findings of strangulation ****.

Lena Camperlengo: Yes, well strangulation yes and suffocation it can happen, but in other cases it's not there.

Shannon Stotenbur-Wing: And that's the really good point with a doll reenactment as well because if you ask in this case and when we did this exercise I went there too and I said well we don't know what the... We don't have scene photos to see what the lividity pattern was. We don't know what the sheets look like, if there was any you know regorge, if there was any blood on the sheets. We don't know if Dad was drinking. We

don't... We're at the local level, so that's the first thing I think of, Dad was drunk. He rolled over on the baby, rolled back, so he may have suffocated the baby and came right back, so that's really the when we talk about the importance of the death scene in totality, not just the doll reenactment, but photos at the scene, taking the baby's clothing, taking the pillow case, taking anything that you can find in order to help you give the medical examiner more information that would lead you more to that area as well.

Audience: Is one of the things you've been asking is **** obese because that sometimes will **** to the issue that actually literally because **** and that's a big... That's a big ****.

Lena Camperlengo: Shavon.

Shavon Artis: I always **** outreach for African-Americans looking at SIDS particularly and in the SIDS one issue that was seen particularly in the rural areas where the death scene investigator or the medical examiner actually knows the family. They admit to the fact that there are cases where they just assign it to SIDS out of respect to the family because they don't want to **** embarrassed because the whole community knows the family and it's a very small community and so just for sheer... You know just for a public expectance they just assign it to SIDS even though they may suspect that it's been actual suffocation or you know **** they just ****.

Lena Camperlengo: Yep, we heard those for sure.

Audience: That goes back to your point about how you educate that family that is going to have more babies.

Lena Camperlengo: Right, exactly.

Audience: Of course we're pretty educated about putting the baby on the bed and not having soft bedding, pillows or blankets. I wonder if they had other children, previous children and just what their education level was.

Lena Camperlengo: So it seems like everybody has burning questions and you're not going to find it. When we did the feasibility study there was a great quote that said, "If it wasn't collected at the scene we don't know." So it really goes back to the foundation of what information is gathered at the scene because going back two to three months afterwards you're just not going to get it, so take home message I guess from our presentations here is get the information at the death scene. And thank you all for participating in our exercise.

Audience: I just want to add one thing and that is our program manager, she hears a lot from parents that say, "Oh, we do this all the time ****." "You don't know what you're talking about." So she has told them well why don't you bake a chocolate cake,

cover it with icing and put that in bed between you and your husband and wake up in the morning and see if you have **** icing ****.

Shannon Stotenbur-Wing: I like that. Yeah, that is good.

Hanan Kallash: Once again, thank you for coming to this session. It is late in the day. It's sort of getting... We were debating whether we'd show up with chocolate and wine, but nobody brought it.

Audience: You have a pocket full of chocolate.

Hanan Kallash: I do have some chocolate. It's mine though. So I'm going to be talking about a couple of particular programs and I'm actually... I have to acknowledge Shavon who is in the audience because it's through a contract with Eunice Kennedy Shriver National Institute of Child Health and Human Development that I can be here today. John McGrath and Shavon Artis are the one that's head this particular program. It's got several components to it and I'm going to try to go through the process by which we came up with this because I think pharmacists would be considered unusual suspects. A term I learned this morning from a session. It's not like... How many of us here do public outreach to pharmacists to get them involved? Nobody. Why not? They're out there. They're in the community. They need to be included in this messaging by the end of this little talk. I hope you'll consider it.

Audience: They're giving ****.

Hanan Kallash: Yes. They are and we're going to talk about how can we involve them.

Audience: *****

Hanan Kallash: Yes, yes, they are. So of course the NICHD doesn't just do you know education to public health professionals. This slide is courtesy of John McGrath. They've had... This timeline demonstrates the different ways that they've progressed in the last you know 20 years of doing this work and you know there at first theory, social cognitive learning. The audience was mothers, fathers, grandparents. The theme was place infants on their backs. That theme hasn't really changed. Product development and then outcomes, the increased awareness of... increased awareness, reduction in SIDS, increase in back sleeping, right. 2001, 2006 the diffusion theory, community organizations, audiences are more the community health workers, leaders, African-American organization, the American-Indian, Alaskan native groups. Themes, reach one, teach one, talk about safe sleep in your sphere of influence and then you know they've done trainings, mini grants, contracts, lots of summits and then the outcomes are increased awareness, the involvement of many national organizations. 2006 to 2009, community organization, media advocacy, a greater focus on the health professional, so not just reaching directly into the community, but now these health professionals. All caregivers need to focus on all aspects of the sleep environment, so

expanding the message and then community forums, having the community participate in the effort and then the organizational promotion of SIDS education risk reduction activities, organizational media promotion.

Now I always start most of my sessions with a compliment towards the audience that sort of hooks them up. Why are we here? Why are we talking to the nurses? Now the nurses and now I am now a nurse. I am a registered nurse. It just happened recently, like two weeks ago and so you know the nurses were an easy in, right. Of course, they're always doing health education. Gallup poll for years has shown that they're a credible source of information. People trust the information and then you've got the pharmacists have also been up there on top and it's like look at your power. Now I'm not talking about pharmaceutical companies. I'm talking about the actual community pharmacist is who these people trust and they ask them questions, so they will go get their H1N1 from the CVS, the Walgreens, Rite Aid. High school teachers, medical doctors are a little bit lower, shocking to me. And I didn't show the full one. You got car salesmen all the way on the bottom.

Now out of all the things that NICHD is doing I'm just going to focus on the health professionals outreach activities. So in 2006 we launched the nursing program and risk reduction strategies for SIDS gives them ways to communicate this information to parents and caregivers and they also released a booklet intended for healthcare providers. Has anyone seen it? I didn't bring a sample, but it's from the healthcare provider's perspective about how to communicate messages to parents, the important

ones and implemented a provider led curriculum education model for pharmacists in 2008, which will be followed by an online print module.

Now the nurse program was like I said a pretty easy sale. Research already supported the need for nursing CEU and provided direction. We had a whole bunch of surveys from A to B. There was all this stuff that was saying nurses knew the information, but it was getting lost in translation and so that's what we did. We came up with a whole curriculum that they sort of related to that was... and I'm going to show you parts of the curriculum because I think that's important regarding what are we doing with education because it really works with communities as well because you know we're in the age of social media where there is so much information out there that the more information... that we want them to get the best information and we want them to think of NICHD as the place to go to get the best. Like this is the last stop for you. If you want the science evidence based information this is where it is at and so with the nursing program we synthesized it, developed the program initiative, get a whole bunch of pieces, delegate, you know because we were the provided led, but then there was somebody else who was doing the exhibits. There was somebody else who was doing the whole curriculum development, getting it online and then implementing it, provider led, learner led and now we're in the maintenance stage of it. It's all learner led now. It's all online. And now the thoughts are we probably should evaluate it on some level. That's always nice. Unfortunately evaluation department is the first one to go.

The collaborating organizations, so you go to the main ones, right. None of these are surprising, the Academy of Neonatal Nursing, ACNM, ASIP, the Association of Women's Health, A1, March of Dimes, First Candle. You know and then we also were very clear in identifying the minority ones, such as the National Alaskan Native American Indian Nurses Association and so we submitted abstracts. We went to these conferences and it probably took us two to three years before they started calling us and so it's great. Now everybody knows about it. They're doing it. It's awesome. And the learning objectives for them were define SIDS, list the critical SIDS risk reduction messages for parents and caregivers, list the four barriers to back sleeping, describe your key role as an educator. And the four barriers were ones that evidence based research said that was most significant to them, which also turned out to be the ones that were barriers for communities in general, such as... Does anybody know what the four barriers might be? Why would people not place their babies on their backs?

Audience: Grandma told me not to.

Hanan Kallash: Right. Who told you where to place the baby? Where are you getting your advice from? Advice from others.

Audience: Choking.

Hanan Kallash: Choking, aspiration. Okay, I know you guys know it. Choking, aspiration, advice from mothers.

Audience: It's not comfortable for the baby.

Hanan Kallash: Right, comfort because the baby is talking to you about comfort because how did they define the comfort? What's their perception?

Audience: How long they can sleep.

Hanan Kallash: That's right. That baby is not sleeping long enough. So we always include you know as part of the teaching there is somehow we didn't translate to them that babies don't sleep that long, especially if we're teaching them about breastfeeding. Should a baby really in the first you know six weeks of life be sleeping more than two to three hours? No and so it's perfectly fine for the baby. You know you walk into a room and everybody is like shh, the baby is sleeping because what are they afraid of? What are we afraid of, the baby waking up? We're not afraid of that. We welcome it. We're like don't be afraid of the baby waking up. It's perfectly fine. We like to see that. And then there is new information relating infant health development because a big concern is well they're not growing if they're not waking up and that is not true. And then we're very specific in helping them describe the ways to effectively communicate the SIDS risk reduction. You know we don't want

you to lecture. We want you to have a dialogue with your clients. This is how it looks and it's live online, so go to that website.

Audience: Could you ****?

Hanan Kallash: Well if you just Google. This is pretty good. I don't know if NICHHD paid Google, but if you just Google NICHHD nurses it's the first one that comes up.

Audience: This is online.

Hanan Kallash: Yes, it's online. You can take it online.

Audience: **** about it. I thought it was ****.

Hanan Kallash: There is an announcement. Do you know what you could do to get the announcements from NICHHD? They have a listserv that you can go onto the NICHHD website and subscribe. You're right though. Shavon, you need to subscribe everybody that we got on the AMCHP list that they sent us because you can unsubscribe, but NICHHD, if you go to the website, yes, there is... You can then subscribe from there. It's actually right on one of their homepages. Are you done? Okay.

So I'm sure this is more. I don't have the update numbers. Shavon sends them to me or tells me about them. Can everybody tell that is a little baby on its back?

Audience: No.

Hanan Kallash: Does it look like a pen? I worked so hard to get that baby on its back bullet point. You should have seen. It looked so silly when it was all like that, but it's a baby on its back, sleeping peacefully. So to date we've had 8,700 have received the CE credits and these are all free credits. It's accredited by the Maryland Nursing Association and that was one of the blips along the way that took a little bit longer. When you're doing a CEU program like this who are you going to get that is not going to make you give up your firstborn for the CEU units and you know those were challenges that Shavon worked out. There has been over 45,000 healthcare provider booklets distributed in 2009 and as I said, the online CEU is now live as of February 26, 2010 and it was a long labor and delivery.

Now the pharmacist program, research supported the idea of a CEU, but little direction because nobody has ever surveyed pharmacists on their knowledge of SIDS, but what we did have is that pharmacists were willing to take on the role of community education. They were a very underutilized healthcare professional and so there was a pilot in DC. We had a really engaged pharmacist who was like, "You know what?" "I want to take this on." "Let's do this." And he partnered and he was able to help get us into the DC Pharmacists Association. And then NICHD because we needed direction for the program, conducted focus groups in Baltimore; Maryland; Jackson, Mississippi and in Jackson, Mississippi there was a specific group that targeted African-American

pharmacists because of course one of the biggest missions of NICHD is addressing the health inequities, the disparities that we face and then of course the process has been the same for the pharmacist programs, synthesize, implement, maintain and we're at the implementing stage sort of. These are some of the pharmacist groups and now the learning objectives are the same. The only different bullet points are the last two, discuss the potential opportunities where pharmacists could serve as educators of SIDS and then describe the opportunities to effectively communicate it.

Infant care, so one of the things that is very important about our curriculum is that we address cultural challenges as well and face the fact that advice from others is really big and we have to make ourselves a credible, the healthcare professional as a credible source of information and like I said the one stop... I can see your please finish sign. I'm almost there. Yes, I know. And so that was very important for us and we're addressing it in numerous ways by involving groups and like I said the best thing about our curriculum is the way we look at the trachea, the esophagus and we relate to them the physiology to the sleep position and then we ask them for a discussion. And then would these actions represent possible roles you could play as pharmacists? Asking the expectant mother, father or family member about how are where the baby will be sleeping, providing education to women during pregnancy about SIDS, providing a Safe Sleep brochure, providing Safe Sleep brochures near the infant formula, sharing Safe Sleep information with your families and community and like I said we had a meeting in DC, the NIH Clinical Pharmacists and Ohio Pharmacist Association meeting. We've had 928 pharmacists have received it and then these are you know. We're out there

working and the thing that we want from you is we want to work with you. If you know about a pharmacist who wants to work with us let us know.

Annette Phelps: Okay, I know we're running really low on time and so I'll try to go through this very quickly, but give you the high points of what we do in Florida. I want to thank especially Sandra, Frank and Mary Adkins because it is in part due to them that I was able to even travel to this meeting today and believe it or not I think Florida was asked to do this presentation with them because we don't have an identifiable SIDS or SUID program. Things have changed in the way that we deliver our services and we have a much more blended model and I think that's what they wanted me to share today.

We have a Healthy Start system in our state. That's our primary NCH program. It was established in 1991 and it was meant to address infant mortality primarily. Some of the other things that it addresses are prematurity and some of the morbidities, but the primary focus was on infant mortality and it involves a system of coalitions across our state who have responsibility for doing a needs assessment and addressing the needs within those communities.

Also within that system we do have 22 FIMR projects and they of course if... How many...? Who doesn't know what a FIMR is and what it does? Anybody? Okay, so I don't have to go through all of that, but they do make recommendations for their communities based on the findings from their reviews. Their experts in their community

review committee then takes those and implements actions in the community. We also have a statewide child abuse death review system that thanks to Terry Covington and Sally Foggerty recently. We have joined forces and we partner and we have regular meetings across the FIMR, the Child Abuse Death Review Leadership Team at the central office and our injury prevention program, so that we're all working together, sharing the information we have and when we find cross sections then we work together to put forward the kind of initiative or implementation plan that we need to do.

You probably from just that little bit of talking understand that we have three main things that we do in Florida related to SUID or SIDs prevention. We do investigating, understanding, training, education and community interventions. First of all, the investigations, we like Michigan have a medical examiner system. We have 24 across the state and we wanted to know what was going on because our SIDS reports were different and we were seeing a lot more unknowns and unspecified, other SUIDS and it had changed every time, but we did not have a real pattern with our medical examiners. We did see some were shifting to that unknown, unspecified, suffocation, strangulation, those kinds of things and what we were seeing is with that shift it was hard for our communities to really assess and implement and evaluate what we needed to do, so we went to the medical examiners and we said hey, we got a problem. David is in the back here and he was there when we did this, when we shared these findings with the medical examiners and we said so what we'd like to do is offer you some training and help you to better understand the kinds of things that are needed in putting these diagnoses that you've heard earlier on the death certificate and they said, "Oh, you

could never train us.” “Just put whatever you want to put on there.” So we went back to the drawing board and we said we’ve got to engage them. Using some of those thoughts that we heard this morning in switch, in that conversation what was the hook that we could get with them, so we went back and we said you know we really might be able to do something about some of these deaths if you helped us, so could we do an investigation that we would look more at those unexpected infant deaths and do some more investigation along these lines and would you join us and do that, so they said yes. So we’re working on that and looking at what we can do.

Another investigation we did was we looked at **** and we wanted to compare the data with risk factors for not using the back sleep position and for bed sharing and what we found was that the risk profiles were very different for these two, so what we decided is that rather than these blanket kinds of trainings that we traditionally offer we needed to do more with assessing what was the issue with that parent and being more focused in what we do to provide the behavior change messages and we also are using some of that brief therapy kind of thinking as far as getting to that behavior change, not just health education.

Training and education, we’ve had a number of partnerships across the state developing educational materials. We also developed a position paper for the department on bed sharing and we have done provider training. We’ve done the traditional brochures. This is very old, but we’ve put out information about not smoking. We’ve done all of those kinds of messaging that we’ve talked about. Recently though

we decided we needed more than just those brochures just that kind of messages and based on the Child Abuse Death Review Team's recommendations for more consistent education the Department of Children and Families was willing to fund developing a broader systematic approach to this education and so they funded the Ounce of Prevention Fund to develop Sleep Right, Sleep Tight, which was a much broader kind of approach. You can find the information from Lonni Perezick at that email address there. That position statement is consistent with the AAP. We felt like that we needed to have something on our website and information that people could go to and they would know what the Department of Health's stand was, so that we could be consistent across our messages.

We found that some of our messaging was not consistent. WIC was saying one thing and Healthy Start might have been saying something else, so we did joint trainings. In translating that research into practice we started to say what some of these studies that I've talked about were finding and what needed to happen as a result. We know that from that Infant Feeding Practices Study that what, 10 to 15% of women ever got a message from their provider and then we also know that like 45% were never told to put their baby on their backs, so we have used that to move us forward with thinking about how we could train physicians and other healthcare providers more effectively, so we have a training plan that will be a webcast. We'll be archiving it and putting it on a DVD and a variety of things coming up in April.

Finally, community initiatives, I talked about that a little bit. We do a variety of services both to individuals in the communities from home visiting, the parent education, providing the resources including cribs. We mentioned FIMR and implementation. The mobilizing the community partnerships and you talked about pharmacies being one of those what do you call it, unusual partners. Well we use beauty shops and nail salons and a variety of others that we train. We've also done some first responder training with the new **** form and we're working with colleges and universities to do the pre service training for professionals. There have been a number of initiatives, specifically Project Moses with churches and mentors and we even go the prison system involved. They made the bassinets and cribs. We've had another thing called Save Our Babies and that was a train the trainer and they did train some of those community people who would your nontraditional partner.

And there is a new... I put some brochures on the back that's draft that's just coming out of Hillsborough County, which is the Tampa area and they're going to be training providers of all different kinds and parents about not just safe sleep, but also about picking out the right care provider and a variety of other things. So you can reach me at that address and that was a whirlwind.

Mary Adkins: Well okay. Guess what? I'm the last speaker. You're all doing very well to hang in this long. Okay, I actually have a fun job. I'm going to talk about all of you. I'm going to talk about what is going on in The States, so but first you have to put up with a little bit of a commercial. I want to tell you all if you... Maybe you know this, but

you know we adults need to hear things many times. I want to talk to you about the four federally funded SIDS, SUID centers and I'm going to... Would you hand these out? Would you mind? There are four, Project IMPACT and I'm here representing Project IMPACT. As you can see our job is to deal with communications. We are a cooperative agreement with ASIP. Sandra Frank is the current president of ASIP. Sandra, raise your hand. The resource center is at Georgetown University and that is... If you haven't been to the resource center website I would encourage all of you to do so. It is a library and they have countless resources. Although this card, the front is Project IMPACT. If you turn it over the websites are there of the other centers, so please, please, please do check them out. I should say Project IMPACT we're the ones that monitor the listserv, so please if you're not on join the listserv. The program support center is at First Candle, that would be Hanan. Yes, she works with the programs there. And then the fourth one is the National Center for Cultural Competence also at Georgetown and I think... Who has got booths here? You do. The resource center does. Does Susanne as well?

Audience: No, NICHD does.

Mary Adkins: NIC... Yes, you do, okay, great. Okay, in this very short time I'm going to do a couple of things. I'm going to do a little bit about the history of SIDS. I'm going to talk about what is going on now in The States and then I'm hoping you all representing states are going to tell me if that is your experience or not. Illustrate the current landscape, but we already heard the Florida story and I'm really glad you were here to

tell it. And then we're going to talk about what is next. What do we need to do now that... with the given landscape? So okay, let's do a very quick, very quick history. 1974... How many of you have worked with SIDS programs, SIDS? Okay, a couple. So did you stand up when he said 30 years last night? Were you there?

Audience: I wasn't there last night.

Mary Adkins: Okay, when Michael Frazier asked people to stand up if you had had maternal child experience and he did what, the five years, the ten years, the twenty, the thirty. No, okay.

Audience: Mary, I think you're the only one.

Mary Adkins: I think I... Yeah the 30. It's probably about 29, but it's darn close to it. Who else?

Audience: ****

Mary Adkins: Really?

Audience: I think 35.

Mary Adkins: 35, you win. Yes, okay. So '74 we get this... the Sudden Infant Death Syndrome Act passed. NICHD is responsible for research. MCH is represents for

information and counseling and there are 21 SIDS projects. In '81 if you have been around at all you've heard the talk about what happened when we moved into block grants and the SIDS programs were also folded into that.

Okay, now we're going to jump way to '94 when Back to Sleep was the big focus. But now between the '74, '81 and '94 what was happening with SIDS programs? If you were working in the field you were doing grief services, right? And we were all very clear on what that meant. Did you do grief?

Audience: I was at the local level during that time. That's what we had as resources was referring **** to **** grief services.

Mary Adkins: Grief service, that's exactly it, right?

Audience: We did the apnea ****.

Mary Adkins: Apnea, that's was another one. Wasn't it? Yeah they were in vogue for awhile and then we found out it really didn't matter much, right? Yeah, we've gone through many iterations, haven't we? So then we get back to sleep and now we're still doing grief services, but now we're beginning the risk reduction, right? It was kind of we have changed now. We have something that we think might make a difference and then of course we move up to present time.

We had the 2000 AAP statement, the 2005 statement, the recommendations for risk

reduction and many of you probably know that the SIDS Taskforce with AAP has reconvened. Dr. Rachel Moon chairs it and they will most likely have a new statement for us to look at well maybe not until 2011 or '12, but there will be revisions.

Okay, now what is going on in The States? If I had to have one sentence that would summarize it it's this one. State public health SIDS activities have evolved from categorically funded singular focus programs to multilayered campaigns and initiatives uniquely crafted by each state and that is an important statement for me. Someone like me who has worked in the field for so many years and really focused on infant mortality because you know in the last couple of years we have wondered are there SIDS programs anymore and actually you Annette said you know in Florida we don't have a SIDS program and the question began to be asked well maybe there aren't any SIDS programs anymore. We're going to find out.

Project IMPACT I mentioned one of the... Part of the mission of Project IMPACT is to understand what is going on in the state programs, convene them, provide technical support and to document what is going on and so we decided that we needed to answer the question what is going on in the local level related to SIDS and SUID programs, so we convened three regional meetings and you can... Oh my God. Okay, I just saw the sign. I'm going to do this very quickly. So these are the states that participated. Are any of you from these states? Okay, okay, so we're going to be talking about you. So we did these states and we... this is the process. We contacted the MCH directors in these states and asked them to identify who in their state would be responsible or have

expertise in SIDS, SUID and we asked them to think about both risk reduction and grief and we said we want you to come to a meeting. We're going to pay your way and but you can only send people who really are your SIDS, SUID people. So they did. All of the three meetings were facilitated and we used the same agenda at each meeting.

So here is some of the findings. The meeting participants represented diverse professional credentials and programs and you can see this isn't all of them, but when we tallied the titles of the participants you see, there is all kinds of folks who came when we asked for SIDS, SUID professionals from the MCH community. Okay, there were 22 states total of all the three regions. 100% of them participate with some kind of risk reduction program and activity. Would you all say that that is true for all of you? All of you are from states... Is there any...? I should ask it the other way. Is there anybody here who doesn't do risk reduction of some kind in your state? You all do.

Audience: Limited.

Mary Adkins: Limited, but you do something, right? What state are you from?

Audience: Arkansas.

Mary Adkins: Arkansas, very good. 55% were able to provide some training on SIDS, SUID, okay. 87%... And this one actually surprised me because I thought we would find a greater gap in the grief. 87% provided SIDS, SUID bereavement services. Now it might be as you've said, limited, but that's a strong showing in my mind. Unfortunately,

only about 14% had the capacity to offer the training. This is what The States want, the states that participated want and I'm curious if this is what you need as well. All 22 states indicated a strong need for national, federal support for information. They want evidence based practices, program development. They want help with messaging and they want mentoring. Now notice they didn't say sustainability, although we talk about that a lot, but I think that states have found ways to do this work, but they need help with these things. Does that ring true? It's been a long day, hasn't it? So just a couple of... Okay, I will finish up immediately.

So one of the other things all of the states said to us, "Please communicate with us." "We can't travel." "Everybody is really having a hard time with training monies, so do webinars." So we said okay fine, we'll do a webinar. Our first one was on February 11 and maybe some of you were on this webinar with Dr. Marion Willinger and Dr. Rachel Moon and I have to tell you that was the day of the snow event in DC or in that timeframe and they had to do it out of their homes because they were snowbound and so we were so pleased that we actually could carry this off, but look at these numbers. 2,531 attempted to register for this webinar. Out of that 1,259 were allowed because the software has a cap on it. And look at the kinds of participants and again, this is just some examples. The list goes on and on, but very diverse group. We heard Florida.

So what I really want you to hear after a very long day is that SIDS programs are alive and well. They're very different from what they used to be, but they're there and we learned that there is a strong vibrant community of professionals who are very

interested in risk reduction and grief. They're looking for some help, but they're there and they have integrated this into their work and I see that as a very strong success story. Now we have challenges and these are some of the things we need to work on. We have a very complicated message now. Back to Sleep was pretty easy compared to what we have to do now. We have to respect the uniqueness and diversity. We need evidenced based practices above everything else.

So in summary, SIDS, SUID initiatives are transitioning. They're integrating into a variety of programs. They involve a diverse group of professionals and many are nontraditional. Pharmacist would be considered probably nontraditional. And states are adapting. They're adapting to risk reduction and grief support activities according to individual state needs and the other thing that I think is really important. Today's SIDS, SUID community is truly positioned to embrace a life course perspective and boy haven't we heard that a lot. So thank you. I know we're a little bit over time. You've been very patient with us. I think if you have questions we'll be willing to stay around for a little bit, but I think that we had better adjourn because I've been told that three times already. So anyway, contact information and thank you so much. Please sign up for the listserv. Please check out the resource centers at their websites.

Audience: And the webinar is available transcripts or PowerPoint.

Mary Adkins: It is archived. It is archived on the resource center.

Audience: What is that website?

Mary Adkins: Look on the back of your little card. And is it on AMCHP's? I think it's...

Audience: It's getting there. **** website too. It was sent to us in the mail and I have yet to see it

Mary Adkins: Really?

Audience: Okay, we'll keep our fingers crossed for the postal service.

Mary Adkins: We had to mail them because it's a very large file, so.