

# Reducing the Risk of Sudden Infant Death Syndrome (SIDS) in African American Communities

A Training Guide for a 60-Minute Community Education Presentation on SIDS

### Reduce the Risk of Sudden Infant Death Syndrome (SIDS)



#### Goals and Objectives

#### Introduction

As a result of this presentation, participants will be prepared to help increase awareness of SIDS in African American communities by talking with others about the impact of SIDS and risk-reduction behaviors.

At the end of the presentation, participants will be able to:

- Define Sudden Infant Death Syndrome.
- Understand the impact of SIDS across the country and in African American communities.
- ◆ Apply the basic "Back to Sleep" risk-reduction practices that help reduce the risk of SIDS.
- Identify and discuss other infant care practices that help babies stay healthy.
- Understand the impact that a SIDS death has on a family.
- Identify ways to increase awareness in their community.
- Know where and how to find more information and community resources about SIDS.

#### Time and Audience Size

This is a **60-minute presentation** that will help you provide an **overview of SIDS**, explain the impact SIDS has on families, describe risk-reduction practices, and identify community resources. This presentation is designed for audience interaction and is recommended for groups of 30 or fewer. Clearly, as discussion increases, so will the amount of time it takes to present the material. Based on the size of your audience, determine in advance if you will have time to take questions during the presentation. If time allows, make yourself available after the presentation to answer additional questions.

#### **Preparation**

Prepare for your training session by reviewing and becoming familiar with the packet before presenting the material.

# Reduce the Risk of Sudden Infant Death Syndrome (SIDS)

(continued)



Put together a stapled packet of handouts 1–12 to give to each participant at the beginning of your presentation. These handouts include the major points that will be discussed during your 60-minute presentation. If you have access to an overhead projector, make overhead transparencies of the handouts to use during your presentation. Otherwise, refer to the numbered handouts as you discuss each one.

The other material found in the Resource Kit provides a wealth of additional information about SIDS that can help you prepare for your presentation. The handouts for this 60-minute presentation are based on these other materials. Depending on the group to whom you are presenting, you may want to make copies of some of these materials. If possible, get a VCR to show the videotape on reducing risk.

To help you identify local resources, contact the SIDS Alliance, the Association of SIDS and Infant Mortality Programs, and/or the National SIDS and Infant Death Program Support Center. They are listed in the "SIDS Resources" section of this Kit. You might want to prepare a list of SIDS organizations and bereavement services as well as other programs that support family health in your community. Your state or local health department may also be able to provide information on additional community resources.

Materials

You will need an easel with paper or a chalk board for the audience participation exercises. You will also need to make copies of the following handouts and information for your presentation. Save the brochures and other resource materials for the end of the session. To order additional brochures, call 1-800-505-CRIB.

Handout-1 Welcome

Handout-2 We Will Talk About . . .

Handout-3 The "Back to Sleep" Campaign

# Reduce the Risk of Sudden Infant Death Syndrome (SIDS)

Handout-4

(continued)



Handout-5	Sudden Infant Death Syndrome is
Handout-6	SIDS Facts
Handout-7	SIDS Myths and Facts
Handout-8	Aspects of Family Grief
Handout-9	How to Reduce Your Baby's Risk
Handout-10	Good Health Care Helps Reduce Many Risks

National Partners

Handout-11 Help Spread the Word Handout-12 Each of Us Can Help

Brochure: <u>Babies Sleep Safest on Their Backs:</u>

Reduce the Risk of SIDS

SIDS Resource List

Local Resource Lists (instructor to provide)
"Saving Babies in Our Communities" article

Order Form for Campaign Materials

#### The Presentation

The essential information in the training curriculum is provided as "Core Content." Presentation tips contain insight and advice to help you in your presentation. **Bold text** in the Core Content is identical to the text in the handouts. This will help you keep your place when you are providing additional information.

## Introductions and Agenda Overview–10 Minutes



#### Handouts & Tips

Handout-1 Welcome

Handout-2 We Will Talk About . . .

Handout-3 The "Back to Sleep" Campaign

Handout-4 National Partners

**Presentation Tip** 

**Audience Participation** 

#### Core Content\*

- ◆ Introduce yourself. Explain your role and your organization's commitment to community education and helping to reduce the risk of SIDS in African American communities.
- Review key points you will discuss and the overall goal.
- ◆ The "Back to Sleep" campaign is a public health education campaign to reduce Sudden Infant Death Syndrome in the U.S.
- The goal of the campaign is to promote back sleeping as the safest sleep position for infants under 1 year of age.
- ◆ These Partner Organizations are committed to helping African American families address a variety of health concerns. Increasing awareness of ways to reduce the risk of SIDS is an important health issue for African American families.
- Reference the national organizations supporting the initiative in your community.

The purpose of this interaction is to help determine what participants know about SIDS and to identify any misconceptions or misinformation they may have. Begin by asking:

"Can someone tell me what SIDS is?"

Write down responses. Then ask:

"What have you heard about SIDS?"

Write down all of the responses and review each one. Clarify any information that is incorrect or partially correct. As you review the responses, state

Bold text in this section is identical to text on handouts.

## Introductions and Agenda Overview (continued)



that you will be covering information pertaining to all aspects of SIDS and that you will answer questions that arise throughout the presentation.

Then ask,

"Does anyone know someone who has lost a baby to SIDS?"

If anyone has, let them know that you will welcome their comments later during the presentation when you discuss the effect that losing a baby to SIDS has on a family.

### What We Know About SIDS-10 Minutes



#### Handouts & Tips

Handout-5 Sudden Infant Death Syndrome is . . .

# Presentation Tip

Handout-6 SIDS Facts

#### **Presentation Tip**

#### Handout-7 SIDS Myths and Facts

**Presentation Tip** 

#### **Core Content**

- ◆ SIDS, sometimes called "crib death," is the number one cause of death in babies between the ages of 1 month and 1 year.
- Scientists have not yet been able to determine the exact cause of SIDS. In most cases, a diagnosis of SIDS is given after an autopsy, death scene investigation, and review of the infant's medical history.
- As you read the definition of SIDS, acknowledge how difficult SIDS is to understand for all concerned people.
- We do know that SIDS is not contagious and is not caused by child abuse, neglect, or "shaken baby syndrome."
- ■Read the "SIDS Facts" handout.
- ◆ Explain that this information has been gathered by scientists, doctors, researchers, and other people who are trying to understand the causes of SIDS.
- ◆ Families really can reduce their babies' risk of SIDS but not "cure" or "prevent" it.
- Read the "SIDS Myths and Facts" handout.
- ◆ Families around the world, including many African American families, have led the way in trying to find the cause of SIDS. Affected families have encouraged the scientific community to learn as much as possible.

### What We Know About SIDS (continued)



# Handout-8

Aspects of Family Grief

- ◆ Families who have experienced this terrible loss often feel guilty and responsible for their baby's death. Yet, the experts who study SIDS are very clear that *no one is to blame* for a SIDS death, and it *cannot* be predicted.
- ◆ SIDS can happen to any family no matter their race, ethnicity, income, or where they live.
- SIDS deaths often create extreme grief reactions in families.
- Guilt and feelings of responsibility. Parents search for things that they did or did not do that might have caused the death.
- ◆ No chance to say goodbye. Because SIDS deaths are unexpected, parents have not had a chance to plan for the death or to say goodbye to their child (as in the case of some heart and lung diseases).
- Siblings' fear of death for themselves or other siblings. Siblings may fear that they too might die in their sleep or that their parents or other siblings may also die.
- **Despair at the lack of answers.** Because we do not know the exact cause of SIDS, it is difficult for families to understand why their baby died from SIDS.
- ◆ Feeling of being under suspicion. Further guilt may be caused by the "suspicion" some families experience during the necessary investigation that follows a SIDS death.
- Extended family's feelings of anger or blame. In an effort to make sense of this unexplainable syndrome, family members may look for others to blame. Others may express anger or fear that the parents did not properly take care of the baby, causing the death.

### What We Know About SIDS (continued)



#### **Presentation Tip**

- As you review some of these issues, speak of the importance of helping families who have lost a baby find resources to support the parents, siblings, and extended family members. Refer to the list of local resources you have compiled.
- ◆ If you know of someone who has experienced a SIDS death, you can share the resource information that has been given to you today.
- ◆ The good news is that there are specific things we can all do to reduce the risk of SIDS in our community.

## Reducing Your Baby's Risk-10 Minutes



# Handouts & Tips Handout-9 How to Reduce Your Baby's Risk Presentation Tip

#### Core Content

- ◆ These risk-reduction behaviors are the ideal in terms of reducing SIDS risk.
- As you discuss each behavior, make sure you provide a full and accurate description of what each behavior means and how to perform it.
- ◆ Place Your Baby on His or Her Back to Sleep at Nighttime and Naptime. U.S. Surgeon General Dr. David Satcher and the American Academy of Pediatrics say that back sleeping is the safest sleep position.
- ◆ People may be skeptical about changing their current practices because they learned them from people they respect and trust. For example, for years doctors (and many grandparents) recommended putting babies to sleep on their stomachs. However, based on the study of thousands of SIDS deaths, we know that back sleeping and these other risk-reduction behaviors can save infant lives.
- ◆ The earlier you put your baby on his or her back to sleep, the more quickly the baby gets used to this position.
- ◆ If your baby cannot sleep on his or her back, discuss other sleep options with your pediatrician or health care provider.
- Placing babies to sleep on their backs is the single most important thing to do to reduce SIDS risk.
- Place Your Baby on a Firm Mattress, Such as in a Safety-Approved Crib. Your baby is safest on a firm surface. Do not place your baby on a soft mattress, sofa, cushion, waterbed, sheepskin, or other soft surface.

### Reducing Your Baby's Risk (continued)



#### **Presentation Tip**

- ► For more information on safety-approved cribs, refer the audience to the Consumer Product Safety Commission's Consumer Hotline: 1-800-638-2772.
- ◆ Some families may not have the money to buy safety-approved cribs. You can still create a safe, firm surface for your baby by eliminating soft, fluffy items from bassinets, cradles, and other sleep areas.
- ◆ Bedsharing poses risks for infants' safety. They can get trapped between the mattress and the structure of the bed or covered by an adult's blankets and pillows. If you choose to have your baby sleep in your bed, make sure you follow all of the risk-reduction recommendations, especially the back sleep position, for safe sleeping.
- Remove All Fluffy and Loose Bedding from the Sleep Area. Make sure that all pillows, quilts, stuffed toys, and other soft items are taken out of the crib and other sleep areas.
- ◆ Some parents may have emotional attachments to a handmade quilt, special toy, or clothing given to them by a cherished friend or family member. Create a safer environment by using these special gifts at times other than sleep time.
- Make Sure Your Baby's Head and Face Stay Uncovered During Sleep. If possible, use only sleep clothing with no other covering for your baby. This keeps the baby's nose and mouth clear during sleep.
- ◆ If you choose to use a blanket, make sure the baby's feet are at the foot of the crib, the blanket is no higher than the baby's chest, and the blanket is tucked in around the mattress, so the baby's head can't get covered by the blanket.
- Some infants who have died of SIDS have been found with soft coverings over their nose and mouth at the time of death.

### Reducing Your Baby's Risk (continued)



- ◆ Don't Smoke Before or After the Birth of Your Baby. Your baby will be safest if you make sure no one smokes around your baby. Studies have shown an increased risk of SIDS in babies whose mothers smoke.
- ◆ Don't Let Your Baby Get Too Warm During Sleep. Babies need to be warm, but not too warm, during sleep. Make sure the baby's room temperature and clothing are the same as what makes you comfortable. Just like you, too many layers of clothing or blankets can overheat the baby and make the baby uncomfortable.
- ◆ Some people fear that babies are more affected by the cold than adults, and so may overdress or cover them in cold weather. But babies are not more sensitive to cold and should not be overdressed.
- Make sure you follow all of these risk-reduction recommendations if you have your baby sleep in your bed.
- Finally, remember that most babies are born healthy and stay that way as they grow.
   Using these risk-reduction practices helps reduce your concern about SIDS so you and your family can enjoy your new baby!
- ◆ SIDS risk-reduction education is not intended to cause greater fear for babies' health, but rather to inform families of the things they can do to help them feel more comfortable and secure about their baby's health.

### Other Practices That Keep Our Babies Healthy-5 Minutes



### Handouts & Tips

Handout-10 Good Health Care Helps Reduce Many Risks

#### **Core Content**

- Much of what you probably do now to protect your baby's health also reduces the risk of SIDS.
- ◆ Get Good Health Care Before and During Pregnancy. Good care for mothers, babies, and families starts even before pregnancy and includes eating the right foods, not smoking, and not taking drugs or drinking alcohol while pregnant.
- Continuing these practices after the baby is born helps maintain good health for the entire family.
- ◆ Some families may not have easy access to health care. Contact your local health department for clinics in your area.

#### **Presentation Tip**

- Provide a local contact(s) for information on health care, if possible.
- Breastfeed Your Baby if Possible. Pediatricians believe that breastfeeding is good for babies.
   Breast milk helps to protect babies from some infections and helps keep babies healthy.
- ◆ Not all mothers *can* or *want* to breastfeed their babies. Health care providers can recommend formulas that will meet all the baby's nutritional needs to maintain healthy growth and development.
- ◆ Take Your Baby for Scheduled Well-Baby Check-ups and Shots. Well-baby check-ups are just that—a way to make sure babies are healthy and remain healthy. These check-ups provide a time for parents to discuss immunization shots for babies and any other concerns about the baby's health and development.
- Some parents may be concerned that immunizations for infants may be dangerous and cause problems rather than cure them. Families with these concerns should talk with their health care provider before making a decision. Many states require that infants receive certain shots.

## Resources for Families and the Community-25 Minutes



#### Handouts & Tips

Handout-11 Help Spread the Word

**Presentation Tip** 

#### **Core Content**

- ◆ Anyone who is involved in the day-to-day care of infants should be aware of back sleeping.
- Review the list of people that your audience can talk with to help spread the word.
- ◆ Unfortunately, babies in the African American community continue to die from SIDS more often than do white babies. An African American baby is currently 2 times more likely to die from SIDS than a white baby. So, spread the word about back sleeping to everyone you come in contact with.
- Remember, no one is to blame for SIDS deaths, but with increased community awareness, the risk of SIDS can be reduced for our generation and future generations.

**Audience Participation** 

Explain to the group that it is sometimes difficult to start a conversation about a health or safety topic, especially when it concerns infants. Tell participants that to help everyone feel more comfortable about "spreading the word," you would like to divide them into four groups to do an exercise on "conversation starters"—things they can say to start a conversation about SIDS.

Ask the following questions:

"How do you think you would start a discussion about SIDS with someone you know?"

"How comfortable would you be talking about SIDS to someone you don't know well?"

Use the following examples to explain how they might start a conversation about SIDS with someone they know.

### Resources for Families and the Community (continued)



"I just attended a presentation on Sudden Infant Death Syndrome. Do you know what SIDS is?"

"Did you know that babies should be placed on their backs to sleep?"

Assign each group one of the following categories—1) new or expecting parents,
2) grandparents, 3) daycare providers, and
4) teenage babysitters. Give each group a sheet of paper (easel paper, if available) and ask them to write down as many "conversation starters" as they can think of to initiate a discussion about SIDS with a person in the assigned category. (If there are more than 30 participants, you may want to add more groups.)

If the groups are having trouble getting started, give them the following examples.

**New parents:** "Did they talk to you about SIDS at the hospital?"

**Grandparents:** "There are so many things that have changed in caring for infants. Did you know that we are supposed to put babies to sleep on their backs?"

**Daycare providers:** "Have you received any material or training about SIDS?"

**Teenage babysitters:** "Have you ever heard of SIDS?"

Give participants 7 to 8 minutes to brainstorm and write down their suggestions. Have someone from each group present the group's suggestions. Ask participants:

"How do you think people will respond to these conversation starters?"

### Resources for Families and the Community (continued)



#### Handout-12 Each of Us Can Help

- When we understand the serious nature of the SIDS problem in our community, each of us can become a valuable community resource.
- ◆ First, Talk About SIDS. Help Increase
  Community Awareness. Many people don't
  understand that SIDS affects the African American
  community in significant numbers. By discussing
  the problem with neighbors, childcare providers,
  health care workers, family members, and others,
  we can help increase community understanding.
- ◆ Then, Talk About Risk Reduction. Share New Ways to Reduce the Risk. Let people know that back sleeping is the single most important thing they can do to reduce the risk of SIDS.

#### Audience Participation

As we've discussed, many people need to know about SIDS and many people can help us raise awareness about SIDS. These include:

People who have infants or care for infants.

Community organizations, clinics, and businesses that might be willing to distribute information about SIDS, such as grocery stores and community centers.

People in the community who are in a position to talk with others about the importance of back sleeping, such as librarians and hair stylists.

Ask participants to think about the people they might contact after the workshop. (Give them about 30 seconds to think.) Ask for volunteers to share the people they have identified and to tell why they selected them.

### Resources for Families and the Community (continued)



#### **Presentation Tip**

- Hold up and show your audience the "Babies Sleep Safest on Their Backs" brochure as a good summary of all the information you've presented. If you were not able to give everyone a copy of the brochure, refer the audience to the toll-free "Back to Sleep" ordering line and the order form for African American campaign materials.
- ◆ And, for additional information on SIDS and the "Back to Sleep" campaign, call the tollfree ordering line at 1-800-505-CRIB.

#### **Presentation Tips**

- If time remains and a VCR is available, you may want to show "Sudden Infant Death Syndrome:
  A Video on Helping to Reduce the Risk."
- Also, if possible, invite participants to ask you questions after the session.



# Sudden Infant Death Syndrome—SIDS

Reducing the Risk in African American Communities

# We Will Talk About . . .



- What We Know About SIDS
- Reducing Our Babies' Risks
- Resources for Families and the Community

# Our Goal . . .

Each participant will be prepared to help increase awareness of SIDS by talking with others about the impact of SIDS and risk-reduction behaviors.

# The "Back to Sleep" Campaign



- The "Back to Sleep" campaign is a public health education campaign to reduce Sudden Infant Death Syndrome in the U.S.
- The goal of the campaign is to promote back sleeping as the safest sleep position for infants under 1 year of age.

# **National Partners**



- Alpha Kappa Alpha Sorority
- American Academy of Pediatrics
- Association of SIDS and Infant Mortality Programs
- Chi Eta Phi Sorority
- Chicago Department of Public Health
- Congress of National Black Churches
- D.C. Department of Health
- Maternal and Child Health Bureau
- National Association for the Advancement of Colored People
- National Association of Black Owned Broadcasters
- National Black Child Development Institute
- National Coalition of 100 Black Women
- National Institute of Child Health and Human Development
- National Medical Association
- Pampers Parenting Institute
- SIDS Alliance
- Zeta Phi Beta Sorority

# Sudden Infant Death Syndrome is ...



The sudden and unexpected death of an infant under 1 year of age for which no exact cause of death can be determined.

# SIDS Facts



- SIDS is the leading cause of death in babies between 1 month and 1 year of age.
- Most SIDS deaths occur in babies who are between 2 and 4 months old.
- Cribs do not cause SIDS, also called "crib death."
- Currently, fewer than 3,000 SIDS deaths occur in the U.S. each year. Before the recommendation to place babies on their backs to sleep, over 5,000 babies died each year.
- More SIDS deaths occur in colder months.
- Babies placed to sleep on their stomachs are much more likely to die of SIDS than babies placed to sleep on their backs.
- SIDS occurs without warning—currently there is no way to tell in advance which babies will die.
- The number of African American babies dying from SIDS has decreased in recent years. However, African American babies are twice as likely to die from SIDS as white babies.

# SIDS Myths and Facts



# Myths

SIDS is not ...

- Caused by vaccines or immunizations.
- "Caught" or contagious.
- Caused by child abuse or neglect.

# **Facts**

Remember that ...

- Cribs do not cause SIDS, also called "crib death."
- SIDS is currently unpredictable, but the risk can be reduced.
- SIDS is sudden and silent—the infant appears to be healthy prior to death.
- A SIDS death occurs quickly during sleep with no signs of suffering.

# Aspects of Family Grief



- Guilt and feelings of responsibility
- No chance to say goodbye
- Siblings' fear of death for themselves or other siblings
- Despair at the lack of answers
- Feeling of being under suspicion
- Extended family's feelings of anger or blame

# How to Reduce Your Baby's Risk



- Place your baby on his or her back to sleep at nighttime and naptime.
- Place your baby on a firm mattress, such as in a safety-approved crib.
- Remove all fluffy and loose bedding from the sleep area.
- Make sure your baby's head and face stay uncovered during sleep.
- Don't smoke before or after the birth of your baby.
- Don't let your baby get too warm during sleep.
- Make sure you follow all of these riskreduction recommendations if you have your baby sleep in your bed.

Finally, remember that most babies are born healthy and stay that way as they grow. Using these risk-reduction practices helps reduce your concern about SIDS so you and your family can enjoy your new baby!

# Good Health Care Helps Reduce Many Risks



- Much of what you probably do now to protect your baby's health also reduces the risk of SIDS.
- Get good health care before and during pregnancy.
- Breastfeed your baby if possible.
- Take your baby for scheduled well-baby check-ups and shots.

# Help Spread the Word



# Talk to . . .

- Parents
- Grandparents
- Aunts and Uncles
- Siblings
- Childcare Providers
- Health Care Providers
- Teachers
- Clergy
- Foster Parents
- ... and everyone in the community concerned about the health and well-being of our babies.

# Each of Us Can Help



- First, talk about SIDS.
   Help increase community awareness.
- Then, talk about risk reduction. Share new ways to reduce the risk.
- And, for additional information on SIDS and the "Back to Sleep" campaign, call the toll-free ordering line at 1-800-505-CRIB.