FirstCandle
HELPING BABIES SURVIVE & THRIVE

Q&A on SIDS

Q: What is Sudden Infant Death Syndrome (SIDS)?

A: SIDS is the diagnosis given for the sudden death of an infant under one year of age that remains unexplained after a complete investigation, which includes an autopsy, examination of the death scene and review of the symptoms or illnesses the infant had prior to dying and any other pertinent medical and family history. Because most babies sleep in cribs, and therefore, most cases of SIDS occur when a baby is in a crib sleeping, SIDS is sometimes called "crib death." Cribs do not cause SIDS. However, other aspects of an infant's sleep environment have been associated with increasing the risks for SIDS.

Q: What causes SIDS?

A: There is mounting evidence that suggests some SIDS babies are born with brain abnormalities that make them vulnerable to sudden death during infancy. Studies of SIDS victims reveal that many SIDS infants have abnormalities in the "arcuate nucleus," a portion of the brain that is involved in control of breathing and waking during sleep. Babies born with defects in other portions of the brain or body may also be more prone to a sudden death. These abnormalities may stem from prenatal exposure to a toxic substance, or lack of a vital compound in the prenatal environment, such as sufficient oxygen.

Q: When is SIDS most likely to occur?

A: SIDS is the leading cause of death in infants between one month and 12 months of age. Most SIDS deaths occur when a baby is between 2 and 4 months of age. Ninety percent of SIDS victims die before 6 months. The risk of SIDS diminishes during the first year of life. The diagnosis of SIDS is not commonly used after 1 year of age.

Q: Is there anything we can do to prevent SIDS?

A: There currently is no way of predicting which newborns will succumb to SIDS. However, there are a few measures parents can take to lower the risk of their child dying from SIDS in order to give their infant the best possible chance to thrive.

Back Sleeping. Placing babies on their backs to sleep is the single most important step that parents and other caregivers can take to reduce the risk of SIDS. Infants who fall asleep on their stomachs should be gently turned onto their backs. Studies have shown that countries where caregivers have switched from placing babies on their stomachs to sleep to placing babies on their backs to sleep have reduced their total SIDS deaths by more than 50 percent. 3,500 fewer infants die of SIDS in the U.S. each year due to this simple measure. It is important to note that the side sleeping position is not a safe alternative. Babies that roll from their side to their tummy are 18 times more likely to die of SIDS.

Bedding. Parents should make sure their baby sleeps on a firm, flat mattress in a crib that meets current safety standards. Caregivers should also avoid using soft, fluffy or loose bedding or other

objects in the crib, and should not use pillows, sheepskins or comforters under the baby. Bumpers are not necessary, and soft or pillow-like bumpers should be avoided. Consider using a sleeper or other sleep clothing as an alternative to blankets, with no other covering. Infants under 1 year of age should not be placed to sleep on an adult bed, waterbed, sofa or with stuffed toys or pillows.

Head Covering. Make sure your baby's head remains uncovered during sleep. Babies are at an increased risk for SIDS if their head becomes covered during sleep. Avoid using a blanket or other covering over your baby's face as a sun or weather screen, or to block out distractions or sounds while your baby is sleeping. Bedding that bunches up or contours around your baby's face can obstruct the mouth and nose, causing potentially dangerous re-breathing of stale air.

Bed Sharing/Sofa Sharing. Do not share a sleep surface with your baby. Bring baby into bed to feed and cuddle, but place them in a separate, safe sleep area alongside your bed when its time to go to sleep. In addition to the recognized hazards presented by pillows and comforters in the family bed, there are risks associated with infants who sleep with parents who are impaired by exhaustion, drug or alcohol abuse, or who are smokers. There are also dangers connected with infants sharing a bed with siblings or relatives other than the baby's mother. Sofas and chairs are particularly dangerous environments for shared sleep. Bed sharing has not been found to be protective against SIDS, though studies suggest that room sharing may be protective. Keeping the baby next to the adult bed in her own separate sleep space for at least the first six months provides greater safety for the infant and proximity for parents seeking to facilitate breastfeeding and share closeness with their baby.

Pacifiers. Recent research has shown that pacifiers can significantly reduce a baby's risk for SIDS. Experts recommend providing your baby with a pacifier EVERY time they are placed down to sleep. While the exact safety mechanism is not yet know, there are many possibilities for this finding. It has been suggested that the presence of a pacifier in the mouth may discourage babies from turning over onto their faces during sleep. Moving or turning may dislodge the pacifier, which may have the effect of encouraging babies to stay on their backs. Another theory suggests that pacifier use might help to keep the tongue positioned forward, keeping the airways open. It has also been hypothesized that pacifier use may quiet a restless infant, who might otherwise move more aggressively around the crib. Pacifiers may also stimulate the upper airway muscles and saliva production, possibly triggering brain activity and ability to arouse from sleep. Increased arousability is seen in infants who usually sleep with a pacifier, even if the pacifier is not being used.

Smoking. Mothers who smoke during pregnancy are three times more likely to have a SIDS baby, and exposure to passive smoke from smoking by mothers, fathers, and others around the baby after its born doubles their risk of SIDS. Parents should be sure to keep their babies in a smoke-free environment. Studies have found that the risk of SIDS rises with each additional smoker in the home, the numbers of cigarettes smoked a day, and the length of the infant's exposure to cigarette smoke. Components of smoke are believed to interfere with an infant's developing lungs and nervous system, and to disrupt a baby's ability to wake from sleep.

Room Temperature. Babies should be kept warm, but they should not be allowed to get too warm. An overheated baby is more likely to go into a deep sleep from which it may be hard to wake up. Keep room temperature at a level that feels comfortable for a lightly clothed adult and avoid overdressing the baby.

Prenatal Care. Good prenatal care – including proper nutrition, abstinence from alcohol, drugs, and smoking, and frequent medical checkups beginning early in pregnancy – has been shown to significantly increase positive birth outcomes.

Breastfeeding. Breastfeeding has been shown to be good for babies by building their immunity against illness and infections, in addition to other benefits. Mothers should be encouraged to breastfeed exclusively for at least the first six months if at all possible.

Data analyzed by scientists at the National Institute of Environmental Health Sciences suggest that breastfeeding can reduce the risk of death for infants in their first year of life. Looking at infants between 28 days and one year of age, researchers concluded that promoting breastfeeding could potentially prevent up to 720 post-neonatal deaths in the U.S. each year. Researchers compared CDC records of 1,204 children who died between 28 days and one year of causes other than congenital anomalies or cancer with those of 7,740 children still alive at one year.

Regular Health Care. Parents should take their babies to their health care provider for regular well baby checkups, and should make sure that their babies receive their immunizations on schedule.

Child Care. Babies who routinely sleep on their backs and are unaccustomed to sleeping on their stomachs are at a significantly increased risk of SIDS when placed prone by a well intentioned but ill-informed relative or caregiver. Be sure to communicate Back to Sleep information to baby sitters, daycare providers, grandparents and everyone else who cares for your infant. Parents cannot assume that everyone knows about Back to Sleep and other ways to reduce SIDS risk.

Q: **What is the Back to Sleep campaign?**

A: Back to Sleep is aptly named for its main recommendation which is to place healthy infants on their backs to sleep to reduce the risk of SIDS. The National Institute of Child Health and Human Development (NICHD) leads the campaign, along with the Maternal and Child Health Bureau and other Federal agencies such as the Centers for Disease Control and the Census Bureau. The American Academy of Pediatrics (AAP) is the major private sponsor, along with First Candle/SIDS Alliance and the Association of SIDS and Infant Mortality Programs. Based on a recommendation made by the AAP in 1992, the campaign was launched in 1994 with an effort to reach every newborn nursery in the country. A toll-free number was established for ordering Back To Sleep pamphlets, posters, and videos.

Q: **Is the campaign successful?**

A: This campaign has been increasingly successful in reaching parents and other caretakers of infants. We have seen a change from 70 percent of babies placed on their stomachs to sleep in 1992 to 15 percent in 2005. The death rate of Sudden Infant Death Syndrome (SIDS) declined by more than 50% between 1994 and 2002, signifying the first significant decrease in SIDS deaths in the U.S.

Q: **Are there any infants that are more at risk for SIDS?**

A: Yes, infants in the following categories are at a higher risk for SIDS:

- Infants born to mothers who are less than 20 years old at the time of their first pregnancy
- Babies born to mothers who had no or late prenatal care
- Infants born to mothers with too short an interval between pregnancies
- Premature or low birth weight babies and multiples
- Babies born to mothers who smoke during or after pregnancy
- Infants who are placed to sleep on their stomach or side

Q: Are any ethnic groups more prone to SIDS?

A: African American infants are nearly two-and-a-half times more likely to die of SIDS than white infants, and Native American babies are approximately three times as likely to die from SIDS. The Back to Sleep campaign is being stepped up, with a special effort to get the message out to these two populations with the help of community, civic and religious groups.

Q: Is SIDS inherited?

A: There may be something that genetically predisposes an infant to higher SIDS risk. Metabolic disorders, which can be inherited, have, at times, been mistaken for SIDS. One such disorder, medium chain acylCoA dehydrogenase deficiency, prevents the infant from properly processing fatty acids. A build up of these acid metabolites could eventually lead to a rapid and fatal disruption in breathing and heart functioning. If there is a family history of this disorder or childhood death of unknown cause (especially more than one case within a family), genetic screening of parents by a blood test can determine if they are carriers of this disorder. If one or both parents are found to be a carrier, the baby can be tested soon after birth at little cost. This is another reason why the autopsy is so important. Tests can be done on the tissues of an infant to identify known metabolic disorders.

Q: Can I place my baby on her side to sleep?

A: Babies who sleep on their sides are actually at an increased risk to die of SIDS compared to babies who sleep on their back, perhaps because babies placed on their sides have a higher likelihood of spontaneously turning onto their tummies.

Q: Won't my baby choke on spit-up or vomit during sleep if placed on his back?

A: Many parents place babies on their stomachs to sleep because they think it prevents them from choking on spit-up or vomit during sleep. But studies in countries where there has been a switch from babies sleeping predominantly on their stomachs to sleeping mainly on their backs have not found any evidence of increased incidence of aspiration, pneumonia, choking, or other problems. In addition, the AAP has reviewed all the scientific literature and found that there is no additional risk of choking on vomit when babies sleep on their backs. Experts actually feel that babies are at a higher risk for choking or aspirating when placed on their tummies than they are when placed on their back.

Q: Which babies should not be placed on their backs to sleep?

A: In some instances, doctors may recommend that babies be placed on their stomachs to sleep if they have disorders such as gastroesophageal reflux or certain upper airway disorders that predispose them to choking or breathing problems while lying on their backs. If parents are unsure about the best sleep position for their baby, it is always a good idea to talk to the baby's doctor or other health care provider.

Q: Doesn't back sleeping cause flat heads?

A: There is some suggestion that the incidence of babies developing flat spots may have increased with back sleeping. This is almost always a benign condition, which will disappear within several months after the baby has begun to sit up. Flat spots can be avoided by altering the back sleeping head position, such as turning the head to one side for a week or so and then changing to the other. Reversing the head-to-toe axis in the crib so the baby's head can continually face outside activity (e.g., the door to the room) helps maintain this position. Parents should be sure to alternate arms when feeding and provide lots of supervised tummy-time while awake (see below). Be sure that your baby does not spend too much time in car seats and carriers to further minimize the potential for a flat head.

Q: Should infants ever be placed on their tummies?

A: As much "tummy time" as possible while the infant is awake and being supervised is recommended for motor development of the upper body muscles. In addition, tummy time may also help prevent flat spots from developing on the back of the baby's head. Never leave your baby unattended during tummy-time. If the baby tires or is sleepy, place them on their back in a safe sleep area.

Q: What if my baby cries and cries and won't sleep in the back position?

A: Positional preference appears to be a learned behavior among infants from birth to 4 to 6 months of age. If placed on their back from day birth, most infants will become accustomed to the back sleeping position.

Q: Should sleeping "wedges" be used for infants?

A: The American Academy of Pediatrics has stated that devices designed to maintain sleep position are not recommended since they have not been sufficiently tested for their safety and none have been shown to be effective at reducing the risk of SIDS.

Q: Are there any advantages or disadvantages to shared sleeping arrangements?

A: Scientific studies have demonstrated that bed sharing, between baby and mother, can alter sleep patterns of mother and baby. These studies have led to a speculation in the lay press that bed sharing or "co-sleeping" may also reduce the risk of SIDS. While bed sharing may have certain benefits (such as encouraging breast feeding), there are no scientific studies demonstrating that bed sharing reduces SIDS. Conversely, there are studies suggesting that bed sharing, under certain conditions, may actually increase the risk of SIDS. There is no basis at this time for encouraging bed sharing as a strategy to reduce SIDS risk. However, room-sharing – keeping the baby alongside the adult bed in his own crib or bassinet – can be protective against SIDS.

Q: Is enough research being conducted to determine the cause of SIDS?

A: Scientists are exploring the development and function of the nervous system, the brain, the heart, breathing and sleeping patterns, body chemical balances, autopsy findings and environmental

factors. SIDS, like other medical disorders, may eventually have more than one explanation – and more than one means of prevention. This may explain why the characteristics of SIDS babies seem so varied. SIDS has been a high priority for research for the National Institute of Child Health and Human Development (NICHD) at the National Institutes of Health (NIH). Although SIDS deaths are decreasing, it is important that NICHD continue to support research aimed at uncovering what causes SIDS, who is at risk for the disorder, and ways to lower the risk of sudden infant death. In addition to its grassroots advocacy program that helps ensure Congressional allocation of adequate funding for NICHD-sponsored SIDS research, First Candle/SIDS Alliance maintains its own national research program.

The more we learn about SIDS, the more easily we will be able to distinguish SIDS from other infant deaths, and perhaps even one day be able to predict more accurately which babies are at highest risk.

Q: Is there any research on home monitors?

A: Among the many avenues of research initiated by the NICHD, infant monitoring was thoroughly investigated by NICHD-funded researchers. In the 1970's and early 1980's, it was thought that monitoring had promise in identifying infants at risk for SIDS and signaling caregivers when infants have life-threatening events that may proceed to SIDS. In September of 1986, the NICHD held a consensus conference titled, "Infantile Apnea and Home Monitoring." After examining all available research, the consensus panel determined that cardiorespiratory monitoring is effective only in some cases to manage apnea. For the normal newborn, the risks, disadvantages, and costs of monitoring outweigh the potential of identifying infants at risk for SIDS.

Today, NICHD funds the Collaborative Home Infant Monitoring Evaluation (CHIME), a multi-center study initiated in 1991 that employs a specifically commissioned monitor with multiple innovative capabilities, including substantially increased memory, detection of obstructive as well as central apnea, continuous measurement of blood oxygen saturation, and assessment of sleep position. The CHIME project will create an extensive database (which will be made available to the scientific community) on the development of cardiorespiratory physiology in normal and in at risk infants. In this context, the study should yield important new insights regarding the frequency and nature of clinically significant events as related to breathing pattern, heart rate, and oxygen saturation.

Q: Does NICHD recommend the use of monitors to prevent SIDS?

A: No. Although some electronic home monitors detect and sound an alarm when a baby stops breathing, there is no evidence that such monitors prevent SIDS. The monitors also pose several disadvantages, including frequent false alarms, restricted mobility of both infant and parents, and the risk of electrical injury to young children.

A panel of experts convened by the National Institutes of Health recommended that home monitors not be used for babies who do not have an increased risk of sudden unexpected death. However, the monitors may be recommended in some cases including for infants who have experienced one or more severe episodes during which they stopped breathing and required resuscitation or stimulation, if the baby is premature and has symptomatic apnea, or if the baby has a medical condition such as central hypoventilation. If an incident has occurred or if an infant is on a monitor, parents need to know how to properly use and maintain the device as well as how to resuscitate their baby if the alarm sounds.

Q: Haven't there been stories of misdiagnoses in the news lately?

A: Research has indicated that a small percentage of cases originally believed to be SIDS were actually caused by a metabolic disorder. Experts agree that misdiagnoses account for a very small percentage of SIDS deaths. In a 2005 policy statement, the American Academy of Pediatrics (AAP) estimated that cases of sudden infant death thought to be SIDS were correct 95-98% of the time.

Q: There have been recent stories in the news suggesting that some cases of SIDS have been misdiagnosed and may be hidden cases of abuse and infanticide.

A: While cases of abuse misdiagnosed as SIDS grab the media spotlight, it is actually far more common for the families or caregivers of SIDS victims to be unjustly accused or suspected of wrongdoing. By medical definition, the term SIDS is a postmortem diagnosis affixed when no known or possible cause for an infant's death can be found following a thorough autopsy, death scene investigation and review of the medical history. Many of the cases reported by the media are decades old, prior to the implementation of proper autopsy and death scene investigation protocol. Although there have been instances of cases that have fallen through the cracks of the medical examiner system, The overwhelming number of SIDS cases are diagnosed correctly, and remain a medical mystery after all known and possible causes, including child abuse, have been ruled out.

These unusual cases only reiterate the need to fully investigate, on a case by case basis, each instance of a sudden infant death and to consider the many possible causes of death, including but not limited to SIDS, congenital anomalies, metabolic disorders, unintentional injuries, child abuse, and infections.

Q: Are there state or national guidelines for investigating the sudden death of infants?

A: A death scene investigation is an integral part of a SIDS diagnosis in order to rule out accidental, environmental, and unnatural causes of death, as well as provide information to aid researchers in developing prevention strategies.

In 2004, the CDC launched an initiative to improve the investigation and reporting of SUID (Sudden Unexpected Infant Death), in collaboration with other federal agencies and organizations representing medical examiners, coroners, death scene investigators, emergency medical personnel, law enforcement officials, SIDS researchers, infant death review experts and SIDS parents. As part of this effort, on March 1, 2006, CDC released the Sudden, Unexplained Infant Death Investigation (SUIDI) Reporting Form for state and local use in infant death scene investigations.

This document includes a model protocol and data form for collection of information by medical examiners, coroners, death team investigators, and police officers. Although state and local ordinances define which deaths must be investigated and the extent of the investigation, these guidelines set the stage for uniform death scene investigation around the country.

Currently, approximately half of the states have mandatory autopsy legislation for the sudden death of an infant that, in many cases, includes support for the administration of compassionate services for SIDS families. Other states are in the process of establishing similar legislation. SIDS families, at the guidance of First Candle/SIDS Alliance, have been at the forefront of efforts urging the funding of research, adoption of mandatory autopsy legislation, and thorough, but compassionate death scene investigations. Broader, standardized implementation of autopsy and

death scene mandates is crucial to efforts to differentiate cases of SIDS from cases of child abuse, and to expand our medical knowledge about SIDS.

Q: How does a SIDS death affect the family?

A: A SIDS death is a tragedy that prompts intense emotional reactions among surviving family members. After the initial disbelief, denial, or numbness begins to wear off, parents often fall into a prolonged depression. This depression can affect their sleeping, eating, ability to concentrate, and general energy level. Crying, weeping, incessant talking, and strong feelings of guilt or anger are all normal reactions.

Many parents experience unreasonable fears that they, or someone in their family, is in danger. Over protection of surviving children and fears for future children are common reactions. As the finality of the child's death becomes a reality for the parents, recovery occurs. Parents begin to take a more active part in their own lives, which begin to have meaning once again. The pain of their child's death becomes less intense but not forgotten. Birthdays, holidays, and the anniversary of the child's death trigger periods of intense pain and suffering.

Children will also be affected by the baby's death. They may fear that other members of the family, including themselves, will also suddenly die. Children often also feel guilty about the death of a sibling and may feel that they had something to do with the death. Children may not show their feelings in obvious ways. Although they may deny being upset and seem unconcerned, signs that they are disturbed include intensified clinging to parents, misbehaving, bedwetting, difficulties in school, and nightmares. It is important to talk to children about the death and explain to them that the baby died because of a medical problem that only occurs in infants and in rare instances.

Q: Are there any support groups available for families who have lost a baby to SIDS?

A: Families are encouraged to seek counseling and support. First Candle/SIDS Alliance can provide bilingual crisis intervention counseling and access to extensive grief resources by calling 800.221.7437, or visiting www.firstcandle.org.

Excerpted and edited by First Candle SIDS Alliance -- August, 2006 from materials developed by the National Institute of Child Health and Human Development (NICHD)

For more information, please contact First Candle at 800.221.7437 or visit us on the web at www.firstcandle.org