WHAT IS SUIDS and SIDS?

Sudden Unexplained Infant Death Syndrome (SUIDS) refers to the sudden and unexpected death of an apparently healthy infant, whose death remains unexplained even after a complete post-mortem investigation, which includes an autopsy, an examination of the circumstances of the death and a review of the case history. Unsafe sleep environments (e.g., bed-sharing, adult bedding/pillows in crib) are frequently observed in many of these deaths.

A subset of these infants may be due to SIDS, Sudden Infant Death Syndrome. These deaths have the same criteria as SUIDS but occur in safe sleeping environments (placed on their back in a crib with a firm mattress and no pillows, etc.). The number of SIDS deaths has decreased in recent years as investigators have recognized the role of sleep position and unsafe sleep environments.

WHAT DOES THE AUTOPSY SHOW AS THE CAUSE OF DEATH?

SUIDS (and SIDS) is reserved only for those deaths, which cannot be explained. An autopsy may answer the family's questions about whether a baby's death was due to some known cause.

If the cause is known, by definition it cannot be called Sudden Unexplained Infant Death Syndrome or SIDS.

In Connecticut, the Medical Examiner and the Police are required by law to perform an autopsy and a scene investigation. In doing so, they may ask many questions and seem intrusive at the time. These steps, however, are necessary for an accurate diagnosis.

WHAT CAUSES SUIDS/SIDS?

No one knows why a baby that seems well can die so suddenly and unexpectedly. Each year brings new theories about what causes these deaths but, as yet, no single theory has yielded the answer that will enable us to prevent these tragic deaths. Unsafe sleep environments are a risk factor for many of these deaths.

There is no evidence to show that SUIDS or SIDS is hereditary or contagious.

WAS THE BABY'S DEATH ANYONE'S FAULT?

No one is at fault for SIDS deaths. Many parents blame themselves, or even each other at first, feeling that the cause was something they did, or failed to do.

SIDS cannot be predicted.

CAN ANYONE TELL WHICH INFANTS ARE AT RISK OF DYING OF SIDS/SUIDS?

The vast majority of SUIDS/SIDS babies are well nourished, well-cared for, and in apparent good health prior to death.

Because medical research has been unable to pin down a cause, there are no definite tests that doctors can give to identify if a baby is at special risk.

Since we do not know of any particular condition that exists prior to death, there is yet no treatment.

DID THE BABY SUFFER?

These babies appear to die in their sleep. Usually no one is aware of the event at the time.

WHAT IF OTHERS WERE CARING FOR THE BABY?

Sometimes relatives, babysitters, or professional childcare providers were in charge of the baby when the death occurred.

Caregivers also feel grief as well as other children who are there when the death occurs.

CAN IT HAPPEN AGAIN IN THE SAME FAMILY?

According to the best available information, there are no two SIDS deaths in a family.

Many parents have brought up healthy children both before and after their baby has died of SIDS.

HOW SHOULD THE BABY'S DEATH BE DISCUSSED WITH THE OTHER CHILDREN?

Children should be told the truth – that their brother or sister died of SUIDS and that only babies die of SUIDS, not older children or adults. Children mostly need to be reassured of their parents' continuing love and affection and of their own safety.

Children may not show their grief in the same way as adults. Parents and caretakers must look for signs of grief in the children. Please talk to your doctor if you have concerns about the child.

WHAT ARE THE EFFECTS OF SUIDS ON THE FAMILY?

People grieve in different ways. The grief affects parents, relatives, siblings, grandparents, and caretakers. The most common feelings are depression, difficulty concentrating, anxiety, anger, denial etc. One may feel one or two symptoms or all of them. It is most important that one looks for support during this difficult time.

"BACK TO SLEEP"

The National Institute of Child Health and Human Development initiated the "Back to Sleep" campaign in 1994. Since then, nationwide there has been a 40 percent reduction in SIDS rates. Other unsafe sleep practices (bed-sharing, pillows) have received increase attention in recent years

and appears to play in role in some of these deaths.

WHAT RESEARCH IS HAPPENING?

Medical research attempts to discover the cause of SUIDS/SIDS so that it may be eliminated, and to identify a baby who may be at special risk, so that some preventative approach may be applied to that particular baby. Specific areas of study include basic functions as heart rate and breathing. An additional area of research is in the field of metabolic enzyme disorders and heart conduction abnormalities.

Probably SUIDS will have more than one complete explanation.

We have many pieces of the puzzle. Now we must find their place in the total picture in order to understand and eventually prevent it.

The local support contacts are:

Connecticut SIDS Alliance
350 Webbs Hill Road
Stamford, CT 06903
866-574-7437
E-Mail: CTSIDS@aol.com

www.sids-network.org
www.sidsalliance.org
www.ctsids.org
www.sids-id-psc.org

State of Connecticut
Department of Public Health
Family Health Division
410 Capitol Ave.
Hartford, CT 06106

The national support contact is below:

The National SIDS Foundation
10500 Little Patuxent Parkway, Suite 420
Columbia, MD 21044
800-221-7437

FACTS YOU SHOULD KNOW ABOUT SUIDS (and SIDS)

It cannot be predicted at this time.

It is not caused by child abuse.

It is not contagious or infectious.

It is not caused by an immunization.

It is not considered hereditary.

It is not a new medical problem.

It occurs rapidly and silently, usually during periods of sleep. The baby does not suffer.

It occurs in families at all social and economic levels.

It probably has more than one cause although the final death mechanisms appear to be similar.

"Back to Sleep" and safe sleep practices can reduce the occurrence of these deaths.

FACTS ABOUT SUDDEN UNEXPECTED INFANT DEATHS

Information for the families from the OFFICE OF THE CHIEF MEDICAL EXAMINER

11 SHUTTLE ROAD
FARMINGTON, CT 06032
(860) 679-3980
1-800-842-8820 TOLL FREE
(860) 679-1257 FAX
http://www.state.ct.us/ocme/