



Dear Expectant SUDC Parent(s) and their Physician:

Families who have experienced the sudden unexplained death of their baby or child often ask, “Should I have my other children tested?” This important question may be followed by the response of “Test them for what?” At this time, we do not know how to predict or prevent SUDC. However, we do know that some rare inheritable disorders can cause sudden unexpected death. We also know that death investigations, as well as state mandated newborn screenings, vary across the U.S. Therefore, it is difficult to recommend one specific set of tests for all families who have suffered an unexplained childhood death.

As with research about SUDC, research in the area of inherited disorders continues. The ability to diagnose and treat individuals with these conditions continues to save lives and maximize the health of those affected. Without diagnosis and treatment, disorders such as Long QT Syndrome and various metabolic disorders would continue to be the cause of sudden unexpected deaths in children and some adults.

Researchers involved with the SUDC Research Project were asked about family testing issues. Recommendations for every family member include following optimal pediatric care which includes, attending well child visits, maintaining current vaccinations, and obtaining appropriate health care when clinically indicated.

In addition, the following information includes tests appropriate for Physicians to consider for families who have suffered the sudden unexplained death of a child.

A new baby often brings some anxiety to parents, but following the loss of a child to SUDC- the anxiety can be very profound. In addition to the “normal” concerns of pregnancy, delivery and life with a new baby, SUDC parents worry about the unknown. What killed my child and how do I protect this baby? Will I ever be able to sleep? Will I always worry that SUDC will strike again?

To ease the transition, The SUDC program has gathered information from our Advisory board, staff and families who have had subsequent children to help.

Share this entire document with your obstetrician and pediatrician in order design a testing plan appropriate for your baby. It will also be helpful to provide these medical professionals with your child’s autopsy report and thorough family history to best help them care for your family. Your pediatrician may recommend other tests in addition to the following, based on your specific family history and the circumstances and information known regarding your child who died.

With continued research, this document will be further refined to provide the best information, care and hope for all families. It is our intent to provide you with medical information pertinent to the care of your baby and some peace of mind as you welcome your baby into the world.

The Sudden Unexplained Death in Childhood (SUDC) Program
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Enclosed you will find information on the following:

- Evaluating Inborn Errors of Metabolism in a Newborn SUDC Sibling
- Evaluating Cardiac Mechanisms in a Newborn SUDC Sibling
- Evaluating Seizures in an SUDC sibling
- Home Monitoring Information for SUDC siblings
- Support for Parents
- Related References

Evaluating Inborn Errors of Metabolism:

During the PRENATAL period:

Get regular and early prenatal care.

Special consideration should be given to the possible occurrence of maternal complications: Acute fatty liver of pregnancy (AFLP); Hemolysis, Elevated Liver (enzymes), Low Platelets Syndrome (HELLP); pre-eclampsia, and others

For the Asymptomatic SUDC Sibling NEWBORN:

Blood

Expanded newborn screening by MS/MS (blood spots)—

If this is not mandated in your state, a bloodspot card from Mayo Medical labs is enclosed. When it is submitted (by your Doctor), be sure it is communicated that this test is for a sibling of SUDC. Your pediatrician will know the specifics of mandated newborn screening in your state, or you can check online at

www.savebabies.org

Urine

Organic Acids (These can be done at your local hospital)

If you require a supplemental newborn screening card, to allow more thorough testing than your mandated state testing program provides, please contact us to send you:

-Mayo Clinic Laboratories' Supplemental Newborn Screening Program Information and bloodspot card

For the Symptomatic SUDC Sibling NEWBORN:

If the newborn is not well — Seek medical attention immediately.

Start evaluation with investigations that include:

Blood Gases, glucose, electrolytes, Lactate, pyruvate, Ammonia

Urine- Organic Acids

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Evaluating Cardiac Mechanisms:

1. A VERY careful and detailed medical history of the decedent with review of the autopsy report and sometimes the autopsy tissue itself
2. A VERY careful and thorough review of the family history with pedigree analysis on both sides searching for the "needles in a haystack"

Screening test in a newborn: Importantly, if a newborn ECG is suggestive of long QT syndrome, it must be repeated as the **false positive rate is high in the first week of life**. If the ECG is persistently abnormal at the 2nd week and/or 2 month well child visit, then strong consideration for the diagnosis of long QT syndrome must be given.

If anything is suggestive of a possible cardiac mechanism: screen siblings and parents with an electrocardiogram (EKG or ECG) and an echocardiogram (ECHO). Long QT Syndrome (LQTS) is a disorder of the electrical system of the lower chambers of the heart (ventricles) and just one type of inheritable disorder.

What is Long QT Syndrome (LQTS)?

By Michael J. Ackerman, MD, PhD

Long QT **Syndrome** (LQTS) is a disorder of the electrical system of the lower chambers of the heart (ventricles). The mechanical or pumping function of the heart is normal. However, the recharging (repolarization) system of the heart is either slow, taking longer than normal to recharge, or inefficient (disorganized). LQTS can be divided into two broad categories: congenital and acquired. In **acquired** LQTS, the electrical recharging abnormality is secondary to medications, abnormalities in electrolytes, or other illnesses (like anorexia nervosa for example) that prolong the QT interval. In contrast, **congenital** LQTS is known as a primary cardiac ion channel disease due to mutations in the genes encoding the proteins (ion channels) responsible for this electrical recharging process. It is estimated that 1 in 3000 persons may have congenital LQTS. The symptoms of LQTS vary tremendously from NO symptoms ever (about 40-50%) to fainting/seizure spells (40-50%) in the setting of exercise like swimming, auditory startles (alarm clocks, phone, doorbells) to sudden death (5-10%). Since the heart's structure and mechanical performance is normal in LQTS, there are no clues found at autopsy. In fact, LQTS should be considered strongly for any sudden unexplained death accompanied by a normal autopsy. An estimated 5 – 15% of sudden infant death syndrome may be caused by LQTS-causing genetic defects. In a postmortem investigation of SUD victims where the average age was 14 years, 20% of the decedents were found to have mutations in LQTS genes. Based upon this data, it is strongly recommended that a careful family history be obtained and screening electrocardiograms of first degree relatives (parents, children, siblings) be considered in the setting of a sudden unexplained and autopsy negative death. Postmortem genetic testing of DNA from the decedent should become the standard of care in the evaluation of SUD but this is hindered presently by the cost of genetic testing and the apparent reluctance of health insurance companies to reimburse for such diagnostic testing despite the potential life saving, not to mention cost saving, benefit for the loved ones left behind.

Commercial testing for the 5 Long QT Syndrome genes is available - www.familion.com (1-866-familion).

Current research has found a greater incidence of channelopathies diagnosed postmortem with the greater age of the child. When a child is of greater age, and when the decedent's autopsy fails to demonstrate any structural abnormalities, then consider the clinical screen for survivors to rule out or assess for the possibility of inherited heart rhythm syndromes.

Evaluating Seizures

Families entering the SUDC Research Project to date are reporting a higher than expected incidence of seizures, especially febrile seizures, in the child who died and sometimes family members as well. Medical literature over the last several decades reports on the benign nature of simple febrile seizures. At this time, we

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recommend a neurological consultation for all SUDC siblings who have a history of seizures (febrile or without fever) or any other neurological concern (e.g., developmental delay) with a pediatric neurologist. The articles below may provide some information and guidance to families and physicians. At this time, since the association between SUDC and febrile seizures is still being investigated, we cannot make any general recommendations about the specific evaluation and treatment of febrile seizures in siblings of children who have died of SUDC.

In the newborn period, as with all babies, a thorough clinical neurological exam by the pediatrician should occur with further clinical intervention if warranted.

Home Monitoring Information for SUDC siblings

Key points:

- **To help reduce the risks of death or illness in any baby or young child attend well child care visits, obtain healthcare when clinically indicated, maintain current vaccinations and follow the *Back to Sleep* and AAP recommendations to reduce the risk of Sudden Infant Death Syndrome (SIDS) and provide a safe sleep environment.**
 - **There are many options for monitoring- discuss them with your Pediatrician.**
 - **There is no scientific evidence that home apnea-bradycardia monitoring prevents infant deaths.**
 - **There has been no research on monitor use for SUDC siblings**
 - **Most SUDC parents choose some form of monitoring for their children into the toddler years. Unless abnormalities are found, there is no need to use home apnea-bradycardia monitors for SUDC newborn siblings after 3-6 months of age.**
 - **Monitors such as video, motion, sound and temperature are available through most baby product stores. These are not medical devices and do not require medical assistance to obtain them. There are no studies on their ability to prevent death.**
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How can you best protect your new baby or other children from dying, when you do not know what caused your previous child's death? This is a difficult question to answer. Clearly, if we knew the cause of SUDC, we could determine whether it was likely to happen again in your family, and we may be able to make interventions to prevent your other children from dying. However, since we do not know the cause of SUDC, and we do not know which children are particularly vulnerable, we do not have specific scientific information that assures us of preventing SUDC in any given child.

However, there are general things that every parent should do to reduce the risks of death or illness in any baby or young child. These include attending well child care visits, obtaining healthcare when clinically indicated, maintaining current vaccinations and the *Back to Sleep* recommendations to reduce the risk of Sudden Infant Death Syndrome (SIDS) and provide a safe sleep environment. The current recommendations (2005) of the American Academy of Pediatrics are listed below.

- Be sure to get good prenatal care and start it early in pregnancy. Do not smoke cigarettes during pregnancy. Do not drink alcohol or use any drugs or medications (including street drugs), which are not prescribed by and discussed with your physician.
- Once your baby is born, be sure that your baby sleeps flat on his/her back for their first year of life. Although sleeping on the stomach is the highest risk for SIDS, side sleeping also has an increased risk. Do not use propping devices to keep your baby on the side. Sleeping on the back is the safest position. Back sleeping has not been associated with an increased risk of aspiration (inhaled material that was spit up). This practice is not necessary after age one-year.

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- Reduce the chance that flat spots will develop on your baby's head. Provide "Tummy Time" when your baby is awake and someone is watching them. Avoid too much time in car seats, carriers and bouncy seats.
- Do not smoke cigarettes around your baby/child. Do not let your baby/child be exposed to any cigarette smoke. Never allow anyone to smoke in the room where your baby/child sleeps.
- Use safe bedding for your baby/child to sleep on. This is a firm mattress, covered with a fitted sheet and without fluffy materials in the crib. Keep all bumpers, quilts, beanbags, soft mattresses, pillows, stuffed animals, etc. out of the crib. Your baby can play with these when he/she is awake, but they should not be around your baby when he/she is sleeping. Do not cover your baby's head with a blanket. It is best to use a one-piece suit for them to sleep in, or place your baby's feet to the foot of the crib and only bring a blanket to the mid-chest level.
- Keep your baby's sleep area close but separate from where you and others sleep. Your baby should not sleep in a bed or on a couch or armchair with adults or other children, but he/she can sleep in the same room as you. If you do bring your baby into bed with you to breastfeed, put him/her back in their separate sleep area, such as a bassinet, crib or bedside co-sleeper (infant bed that attaches to adult bed) when finished.
- Do not let your baby get too hot. Temperatures that are comfortable for you are best for your baby. Dress your baby like you dress yourself. If it is hot outside, and you are wearing cool clothing, dress your baby in cool clothing as well. This is less important after one-year of age. Keep your baby's room at a temperature that is comfortable for an adult.
- Breastfeed your baby if possible. Human milk has a number of health benefits for your baby.
- Recent studies have shown a decreased risk of SIDS among babies who use pacifiers. Think about using a clean, dry pacifier when placing your infant down to sleep, but don't force the baby to take it or reinsert it once the baby falls asleep. If you are breastfeeding, wait until your baby is 1 month old or is used to breastfeeding before using it.

These recommendations have been shown to reduce the risk of SIDS in all infants. Therefore, we recommend them for siblings of SUDC children as well.

Some Home Monitoring Options at a glance:

- A home apnea-bradycardia monitor is a medical device, prescribed by a Doctor that records chest movement (breathing) and the baby's heartbeat. The word "apnea" means a period of not breathing, and the word "bradycardia" means slow heart rate. However, the monitor's computer can detect high and low rates of both breathing and heart rate. Doctors can download the data it records to determine if the baby is having any episodes of concern.
- Sound Monitors- Available at most baby stores. They have a microphone that allows you to hear sound in the room with the baby by carrying a remote receiver.
- Temperature Monitors- Are included in some of the new sound, video and motion sensors.
- Video Monitors- Allows you to see what is going on in the room from a remote location.
- Motion Sensors- Detect motion of the baby often by a force plate placed under the mattress. Nothing is attached to the baby. If no motion is detected for more than 20 seconds, then an alarm sounds. It also has a green blinking light when it detects motion.

Medical Device: The Apnea-Bradycardia Monitor

Many SUDC parents ask about the use of a home apnea-bradycardia monitor to alert the caregiver should a life-threatening event occur, and/or to reduce parental anxiety.

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A home **apnea-bradycardia monitor** is a medical device, which connects two electrodes to your baby's chest with a soft band or tape. The electrodes monitor your baby's heartbeat and movement of the chest (breathing). The monitor sounds an alarm if the heart rate goes below a set rate or if the baby's chest does not move for 20-25 seconds (apnea - or period of not breathing). However, these monitors are not perfect. They monitor movement of the chest, not air going in and out of a baby's lungs. A baby can have an obstructive apnea (tongue falling back against the back of the throat blocking the airway) in which the baby's chest is still moving. The monitor

will think the baby is breathing, and it will not sound an alarm. In addition, there can be a number of "false alarms", where the monitor sounds an alarm, but nothing is actually wrong with the baby. **The monitor does not do anything to save your baby.** The monitor sounds an alarm, and the parent needs to come to the baby, observe to determine if the alarm is real, and then intervene by arousing the baby or performing CPR if necessary.

Though studies have been conducted, there are no studies, which show that home apnea-bradycardia monitors prevent death in SIDS siblings (reference: CHIME study). In contrast, there have been no studies which have evaluated SUDC siblings and monitor use, and therefore there is no data of their use on this rare population is limited. In their 2005 policy statement, the American Academy of Pediatrics does acknowledge the benefits of apnea-bradycardia monitors to "allow rapid recognition of apnea, airway obstruction, respiratory failure, interruption of supplemental oxygen supply, or failure of mechanical respiratory support."

However, we do know that some babies have died while using home monitors, and their use did not prevent a SIDS death. Research studies have shown that babies have apneas (periods where the baby stops breathing) earlier than the peak age when SIDS occurs (2-4 months). Therefore, these types of apneas do not seem to be related to SIDS. Because these monitors are made for infants, they do not work as well for toddlers and older children. They can have frequent false alarms, and they do not accurately detect apneas in older children.

It should be emphasized that the only research to date is on siblings of SIDS infants, not siblings of SUDC children. Since we do not know the cause of SUDC, this leaves open the possibilities for diagnosis and management. Some physicians may prescribe home apnea-bradycardia monitors for infant siblings of SUDC children for the first few months of life as a diagnostic test to see if the baby has any apneas or bradycardias. There are no research studies to support or refute this practice, but it is reasonable to consider. Parents should discuss this with their pediatrician.

Since the goal of such monitoring is to see if a baby has any apneas or bradycardias, it is probably sufficient to monitor babies for the first 3-6 months of life, even though the SUDC child died at an older age. If a baby shows apnea or bradycardia alarms, which are real, then this may prompt further diagnostic testing. Since home apnea-bradycardia monitors do not work as well for toddlers and older children, the primary benefit would be to use these from birth until 3-6 months of age.

Psychological Factors to Consider

SUDC parents may require home monitors for emotional reassurance. They want to know that if an event occurs- they can respond as quickly as possible. It has been suggested that SUDC parents may be sufficiently anxious about suddenly finding their subsequent baby dead and that the use of a home monitor will reduce their anxiety and improve their parenting. There are no studies that have objectively evaluated the results of anxiety among parents who chose to use monitoring devices compared to those who do not.

Non-Medical Monitoring Devices Many SUDC parents report, using some form of monitoring, and often beyond the age of the death of the SUDC child, which may be well into the toddler years. Parents consider their child's medical need for apnea-bradycardia monitors, as well as the effectiveness of "over the counter" monitors available through baby stores.

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Of these commercially available monitors, parents often consider using a **motion sensor type monitor**. An example is the “Angel Care” monitor. It senses **motion, sound** and also has a **thermometer** in the newest version. The Angel care utilizes a force-plate that is positioned under the mattress, and on top of box spring. Sometimes to improve sensitivity, a piece of plywood is recommended over the box spring and under the force plate and mattress. It detects motion of the baby through the mattress. Unlike the apnea monitor, nothing is attached to the baby, There are **video monitors** as well as simple sound monitors. None of these monitors are perfect. There are no studies on their ability to prevent death and parents should be fully aware of this when choosing how to monitor and supervise their child’s sleep. However, if parents, understanding this, derive reassurance, reduced anxiety, and rest, they may be an advantage.

SUDC parents can understandably report feelings of anxiety related to sleep related issues in their living children as a result of finding their child dead after a sleep period. They may worry each time they walk into their new baby’s room: “What will I find? Will they be alive?” Sometimes the use of a monitor may help with these issues. However, some families find the occasional false alarms increase their anxiety. As in grief, each person copes differently and therefore there is no one recommendation for all. Families may consider several options to help them achieve a peaceful, safe and hopeful home environment after the death of a child.

In summary, the best thing you can do is to obtain optimal pediatric care for your child and follow the Back to Sleep recommendations in the first-year of life. This is for all children, and therefore includes siblings of SIDS and SUDC. There is no scientific evidence that home apnea-bradycardia monitoring prevents infant or child deaths, and therefore it is not recommended for prevention of SIDS or SUDC. However, due to a lack of research on SUDC siblings, some physicians and parents may wish to use home apnea bradycardia monitors for diagnostic reasons, and/or emotional reassurance. In these instances, the monitors need not be used after 3-6 months of age unless abnormalities are found. Other types of monitors such as video, motion, sound and temperature are also available through most baby product stores. These are not medical devices and do not require medical assistance to obtain them. Ultimately, parents considering the use of monitors for their SUDC sibling should discuss all these issues with their pediatrician, who can help them make a choice based on their specific situation and needs.

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Support for Parents

After a family has suffered the death of a child to SUDC, the decision to have another child can be daunting. Pregnancy can often bring a mix of hope, excitement, anxiety and stress. These feelings often permeate, in some fashion, through the newborn period and the early years of life. Parents often describe the time as “bittersweet”. They may have feelings of happiness for their precious new child, but tremendous sadness that the child who died is not there. It is another definable mark that life is going on, despite their immense loss.

Parents may also express new concerns regarding their ability to be “good” parents. They may worry that they will be so overprotective of their baby that they will create an environment that limits their child’s freedom and creativity. They may fear that “it” will happen again. Parents often think- “if doctors can’t tell me why my child died, how can anyone be sure it won’t happen again?” They may be afraid to love this child, in fear of being hurt again if this child were to die too. At times, the worry can seem all-consuming and be compounded for Moms by the hormonal shifts of pregnancy and the postpartum period. These are feelings that most parents cannot understand, unless they have had a child die.

Since its creation, The SUDC program has provided support and information to hundreds of families. It is important for parents to now they are not alone. Many of these families have subsequent children that grow up to be thriving, happy and healthy people. Some of these families volunteer in our **peer support program**, and can be a comforting and hopeful ear for families experiencing pregnancy and when caring for a new baby. We also have an **online email group** especially for parents who are expecting or are caring for a new baby. Please contact the SUDC Program with any concerns or questions you may have. Know you are not alone.

The SUDC Program offers the above information as a starting point for discussions with your personal doctor, who knows your family best. It is not meant to be sufficient for all families who have suffered an unexplained death due to some of the reasons mentioned at the beginning of this document.

This document has been amended to describe information pertinent to the evaluation of newborn siblings. More information on the evaluation of family members of all ages, as well as the child who died, is available on our website at www.sudc.org or by calling 800-620-SUDC.

If, at any time, contact with the SUDC Program for more information and/or direct contact with our researchers or physicians would be helpful in evaluating these children, please call Laura Crandall at 800-620-SUDC.

We are extremely grateful for the following Physicians who helped make this document possible.

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In closing, congratulations on your pregnancy! We hope that the information provided can help you enjoy this time to the fullest. Please let us know when their birthday arrives, and do not hesitate to contact us if you have any questions or we can be of any help.

Wishing you all the best!

THE SUDC PROGRAM

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More information can be found on the web at:
<http://www.mayomedicallaboratories.com/articles/newborn/index.html>

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<http://www.mayomedicallaboratories.com/media/articles/communique/mc2831-0903.pdf>

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