

## INFANT APNEA MONITORS FOR SIBLINGS OF SIDS VICTIMS

by  
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Like other things in medicine, infant home apnea-bradycardia monitoring was once thought to be a good idea. If a baby could die because she stops breathing during sleep, what better way to go than to place a device on the baby which will sound an alarm if she stops breathing for 20-seconds or if her heart rate falls below 60-80 beats/minute (depending on age)? Research by Al Steinschneider, Dorothy Kelly, and others suggested that some babies were found not breathing, but could be resuscitated, and that these babies were at risk to do this again. The term "near-miss SIDS" was used to describe these babies, because it was thought that they would have died from SIDS had they not fortuitously been found, revived, and "saved". Hence, the boom in home monitoring occurred beginning around 1980, and it continued well into the 1990's and even after 2000. However, the use of home monitoring was not ever based by any scientific studies to show if they could prevent SIDS. With respect to SIDS siblings, who were once thought to be at increased risk of dying from SIDS compared to the general population, more recent studies suggested that their risk of SIDS was the same as the general population, that is, it was not increased.

In the early 1980's, our group (and others) showed that babies could die even if they were being monitored. That is, monitoring did not prevent death in all patients. At around the same time, David Southall in the United Kingdom performed a large study showing that apnea, periodic breathing, and low heart rates did not predict babies who would subsequently die. Studies in the U.S. confirmed these results. Other studies showed that home monitoring had little impact on SIDS rates or the numbers of babies dying from SIDS. All of these findings started some researchers questioning whether home monitoring in fact did anything.

In the 1990's, we were privileged to be part of the National Institutes of Health (NIH) funded multi-center study called the CHIME Study (Collaborative Home Infant Monitoring Evaluation). The study was designed to find out what actually happened to "high risk" babies who were placed on home monitors. A custom monitor was designed for this study and used to monitor over 1,000 babies for the first 4-6 months of life. A lot of information was derived from this study. However, the hypothesis of the study (that SIDS siblings, preterm infants, and infants with apparent life-threatening events [previously near-miss SIDS] were at increased risk of having significant cardiorespiratory events compared to control infants) was found to be false. Specifically, SIDS siblings, who were born at term, had no more apneas or bradycardias than healthy control infants. Further, the 20-second apneas, which sound alarms on conventional home monitors, were so common, even in healthy normal infants, that they were essentially of no significance, and certainly did not predict death. The CHIME study, in addition to other findings, turned the whole infant monitoring world upside down. Shortly after that, the American Academy of Pediatrics, based largely on the CHIME study results, did not recommend home monitoring, except for specific high risk groups (which does not include SIDS siblings; references for these papers are cited below).

The following recommendations are now made for subsequent siblings of SIDS victims:

- Based on our current information, babies born into a family where a baby has previously died from SIDS are at about the same risk as the general population. This is currently approximately one-in-2,000 live births. Also, based on our current information, there is nothing you did or did not do which caused your baby to die. There is nothing you could have done to prevent your baby from dying. SIDS is a natural cause of death, although we still do not know how SIDS deaths occur.
- During your pregnancy, do everything you can to have a healthy baby. Begin prenatal care early. Follow your obstetrician's advice. Do not smoke during pregnancy. Do not drink alcohol or take illicit substances (especially opiates or cocaine).
- When your baby is born, be sure to follow the "Back to Sleep" recommendations. These have been shown to decrease the number of babies dying from SIDS. Especially be sure to have your baby sleep on the back, use safe bedding, avoid cigarette smoke exposure, do not overheat your baby and breastfeed if possible.
- There is no testing that can be done which will predict whether or not a baby will die from SIDS. Therefore, performing sleep studies, ECGs, etc., are not helpful, and they will not predict whether or not your baby will die.

- Find a pediatrician who is sensitive to the fact that you had a previous baby die from SIDS, and who will take your concerns seriously. The best test to identify health problems is a good history and physical examination by your pediatrician. It may be that his or her evaluation will suggest the need for some testing. Testing which is directed by a pediatric evaluation is more likely to be useful than the indiscriminate use of tests.
- Home monitoring has not been shown scientifically to prevent SIDS recurrence in SIDS siblings.
  - The CHIME study suggests that asymptomatic siblings of SIDS victims have the same apneas as healthy control infants without a family history of SIDS. Home monitoring works by detecting an apnea or bradycardia, and alerting the caregiver, who must then respond and revive the baby if necessary. However, SIDS siblings do not have more apneas or bradycardias than normal infants. Therefore, it does not make sense to use home monitors to try to reduce the incidence of SIDS detected as apnea or bradycardia. We do not recommend the use of home monitors in SIDS siblings, as there is no evidence that it will prevent SIDS.
  - It has been suggested that SIDS parents may be sufficiently anxious about suddenly finding their subsequent baby dead that the use of a home monitor will reduce their anxiety and improve their parenting. There is no evidence that the use of a monitor will reduce anxiety or improve parenting. In fact, there are many stresses caused by the use of home monitoring. If you are the caregiver of your baby alone, you can not do loud activities (such as vacuuming, taking a shower, playing loud music, etc.), which may prevent you from hearing a home monitor alarm. It is difficult to find baby sitters who are trained and skilled in infant cardiopulmonary resuscitation and the graded response to monitor alarms. Thus, parents are stressed with the continuous responsibility of caring for their "high risk infant", often without respite. Therefore, home monitoring is not recommended for the purpose of reducing parental anxiety, as there is no evidence that monitors will do this.
  - If a family is interested in home monitoring despite the above, this should be discussed with your pediatrician. There are no guidelines for how long home monitoring should be used. If a home monitor is used, it has traditionally been recommended for the first 6-months of life, since 90%- 95% of SIDS occurs during that time. Most health insurance and MediCal or Medicaid will not pay for home monitoring of a SIDS sibling, because it is not a treatment for something actually wrong with the child. Therefore, families using home monitoring will usually have to pay for this out of pocket. However, its use is not recommended.

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Publications referenced in this commentary are available upon request from the California SIDS Program and include:

Ramanathan, R., et al. "Cardiorespiratory Events Recorded on Home Monitors: Comparison of Healthy Infants With Those at Increased Risk for SIDS." *Journal of the American Medical Association*, May 2001; 285(17): 2199-2207.

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