

Sudden Infant Death Syndrome

South Carolina

March 15, 2002

Dear :

Sudden Infant Death Syndrome (SIDS) is one of the leading killers of healthy babies in the United States. SIDS is a devastating experience for many parents and child care providers, yet programs in South Carolina addressing this issue are very limited or non-existent in some counties. The purpose of our *SIDSeminars Program* is to provide comprehensive SIDS education and public awareness efforts to the community and to professionals who are impacted by the problem. This program will be the first important step in reducing the traumatic effects of SIDS deaths on families in South Carolina.

The newly formed SIDS Alliance of South Carolina is the only statewide organization dedicated to Sudden Infant Death Syndrome. As a growing organization, we are just starting to have an impact in reducing the problem of SIDS across the state.

Your assistance will ultimately reduce the number of sleep-related infant deaths throughout South Carolina. We appreciate your consideration of this proposal and are eager to provide more detailed information.

Thank you for your time and consideration!

Sincerely,

Linda Gill
Executive Director

INTRODUCTION

The purpose of the *SIDSeminars Program* is to provide comprehensive education and public awareness initiatives to the community and to professionals who are impacted by Sudden Infant Death Syndrome. SIDS is a devastating experience for many parents and child care providers in South Carolina. Until now, there has not been an organized statewide effort providing education and information about SIDS. The goal of this program is to reduce the risk of SIDS and to produce a knowledgeable public which is not blaming, but rather supportive when dealing with Sudden Infant Death Syndrome.

NEED STATEMENT

Imagine the following scenario. Two weeks ago, after taking her morning shower, three-month-old Sammy's mother goes to check on the baby because he hasn't awakened yet for his feeding. She discovers her infant son blue, cold, and not breathing. She screams, grabs the baby from the crib, and runs crying hysterically to the phone to call 911. Her four-year-old son watches terrified as she attempts vainly to revive the baby. She and her son are alone until EMS arrives. Soon after, the police arrive and begin questioning her. All she can think is: *Is my baby dead? Why won't they let me see him? Why do they have to ask me all these questions right now? Can't they see I can't think?...can't believe what is happening? Will they think I am a bad mother?...or did something to him? Surely this is a bad dream and I'll wake up!* She is in shock. She is told that the baby is dead, and the cause of death might be SIDS. She thinks, *Isn't SIDS when a baby suffocates? Why didn't I check on him sooner?!* The shock soon turns into a devastating reality of self-blame, guilt, and depression!

Formerly known as "crib death," Sudden Infant Death Syndrome (SIDS) is defined as "...the sudden death of an infant from two weeks to one year of age which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and review of the clinical history" (Willinger, 1991). Currently, there is no way to know which babies will die from SIDS or how to prevent it. It can strike any family at any time! There are ways to reduce the risk of SIDS, but the fact remains that babies who have *no risk factors* still die silently from it. As a result, *all* newborn infants are potentially at risk for Sudden Infant Death Syndrome in spite of parents "who do everything right." Unlike victims of other medical disorders, *all* SIDS victims die!

SIDS is one of the leading killers of healthy infants in the United States, claiming the lives of over 4,000 babies per year. The situation in South Carolina is even worse! Since 1990, the national infant mortality rate has improved significantly and has decreased by almost 20%, yet South Carolina has not followed this trend. The state continues to have the 7th highest infant mortality rate in the nation and has over 16% more infant deaths than the national average! Obviously, Sudden Infant Death Syndrome is an alarming and devastating problem in South Carolina, yet until now the state has had no organized program which provides comprehensive information about SIDS.

The mystery and lack of understanding about SIDS lead many of those involved with the families of victims to assume that some accident, negligence, or abuse must have occurred because people think "healthy babies don't just die without a reason." By law, so much necessary emphasis is placed on reducing the incidence of child abuse and neglect that many law enforcement and emergency medical service agencies in the state stress the components of investigation rather than the skills needed to conduct it compassionately. Immediately following the deaths of their babies, many families have experienced the additional horror of blame-producing questions like: *Did you shake the baby? Why was the baby sleeping on its stomach? How long had it been since you checked on your baby?* Parents often perceive that the purpose of investigation is to find out what they did wrong.

Without intervention, parents and child care providers of SIDS victims will continue to experience misunderstanding, insensitivity, and blame as they interact with professionals and their community. Sudden Infant Death Syndrome is a traumatic event for families and child care providers. It is a trauma that can be reduced with proper intervention and support.

PROGRAM STRATEGY

The *SIDSeminars Program* was created out of a response to fill the gap in South Carolina of misinformation and confusion regarding SIDS deaths. The newly formed SIDS Alliance of SC is the only statewide organization dedicated to Sudden Infant Death Syndrome. The purpose of our proposed program is to provide comprehensive education and public awareness initiatives to the general public and professionals who interface with the problem of SIDS. Ultimately, our goal is that parents and child care providers impacted by Sudden Infant Death Syndrome experience the support and sensitivity they need in the face of their infant's death. The following outlines the basic proposed program components:

■ **Development of an Advisory Committee:** Initially, we will organize a committee of at least six representatives including law enforcement officers, emergency medical services personnel, health professionals, and parents and child care providers who have experienced SIDS. This committee will monitor and evaluate the program on a monthly basis.

■ **Enhancement and Coordination of Services:** A Community Education Coordinator experienced in SIDS education and support will oversee the program.

■ **Target Group:** This program will focus on community groups throughout South Carolina who may interface with the problem of SIDS or other sleep-related infant deaths. Targets will include parents, child care providers, law enforcement officers, and emergency medical service workers.

■ **Program Activities:** Activities will focus on increasing information about risk-reduction, dispelling misinformation, raising positive awareness, and supporting the grief process of those who experience SIDS. Activities will occur in three main phases of development. The first year will be a pilot demonstration, and as the program is refined and developed, additional participants will be targeted. In *phase one*, an informational brochure and educational packets about Sudden Infant Death Syndrome and the Alliance will be created and sent to the target groups. *Phase two* will involve developing a professionally video taped education program about SIDS issues. The final *phase three* will be to develop and present seminars for professionals, parents, and child care providers. The curriculum will be developed and refined by the coordinator and the advisory committee. Seminars will be conducted twice a month at law enforcement and emergency medical service agencies and health departments across the state.

■ **Dissemination of Information:** It is important that all organizations dedicated to Sudden Infant Death Syndrome and other sleep-related infant deaths work collaboratively to combat the problem. As we implement our program, it will be important to share this information with other SIDS organizations throughout the country. A manual will be available at-cost outlining how our program has been implemented. As video taped seminars are developed, these will be made available to other organizations.

■ **Benefits:** There are numerous benefits of this program. *First*, educational efforts will develop a knowledgeable public which is not blaming of families of SIDS victims. *Second*, parents and child care providers in the face of a sleep-related infant death can find support systems in the community. *Third*, instead of separate entities reaching for the same goals, community groups will collaborate together to reduce sleep-related infant mortality in South Carolina. Eventually, development of a seminar curriculum and an educational video will decrease costs while still reaching a large number of professionals and community groups across the state. *Finally*, with proper education, we will ultimately reduce the number of sleep-related infant deaths across the state.

The SIDS Alliance of South Carolina is a growing organization. In the two years since its formation, strides have been made toward a statewide, collaborative effort to address the issues surrounding SIDS and other sudden, sleep-related infant deaths. The *SIDSeminars Program* will provide an avenue for valuable resource information and education about Sudden Infant Death Syndrome. We have just begun

to have an impact in South Carolina, and *with your help*, we will continue to provide SIDS services throughout the state.

	Requested Funds	Local Contributions	Total Costs
I. PERSONNEL			
A. <i>Community Education Coordinator</i> (contracted part-time)- development of informational packets, seminar curricula, and teaching and coordinating seminars @ 15 hours per week x 50 weeks @ \$13 per hour	\$ 9,750		\$ 9,750
Subtotal Personnel	9,750	0	9,750
II. EQUIPMENT			
A. <i>Computer equipment</i> including CPU/monitor, laser printer, and software for word processing, brochures, and curriculum. This will be donated by the Alliance.		2,905	2,905
B. <i>Camcorder/VCR/Monitor</i> will be used to develop and record educational seminars.	1,155		1,155
Subtotal Equipment	1,155	2,905	4,060
III. TRAVEL			
A. <i>State travel</i> includes transportation for Coordinator to training sites: 708 miles per month @ .25 per mile = \$177 per months x 12 months	2,124		2,124
Subtotal Travel	2,124	0	2,124
IV. CONTRACTUAL			
A. <i>Office space</i> for project coordinator already exists through Alliance for preparing curricula and SIDS information: \$300 mth x 12 mths		3,600	3,600
B. <i>Telephone</i> for line to communicate with participants and organize locations: \$41 month x 12 months	492		492
C. <i>Seminar space</i> donated by local law enforcement, EMS, and health departments: \$98 month x 12 months		1,176	
D. <i>Printing</i> : 5,000 brochures=\$325 total; 100 educational packets w/50 pages @ 3.5¢ per page=\$175; curricula for each class with 22 pages per class @ 3.5¢ per page=77¢ per participant x 15 participants=\$11.55 x 12 classes=\$138.60.	639		639
E. <i>Mailing Lists</i> - purchase lists to send to target groups: 5,000 labels @ \$100 per 1,000 = \$500.	500		500
E. <i>Mailing</i> of brochures and educational packets - 5,000 brochures @ 32¢ each = \$1,600; 100 educational packets @ \$1.28 per packet = \$128.	1,728		1,728
F. <i>Professional Video</i> will be developed by the SC Educational Television (SCETV) at no charge to Alliance.		4,372	
Subtotal Contractual	3,359	9,148	12,507
V. SUPPLIES			
A. <i>General office supplies</i> such as pens, disks, paper, etc.: \$82 month x 12 months	720	264	984

B. <i>Video tapes</i> to record training seminars: 2 seminars month x 12 months = 24 seminars x \$1.78 per tape	43		43
Subtotal Supplies	763	264	1,069
TOTAL DIRECT COSTS	\$17,151	\$ 12,317	\$29,468