



California Sudden Infant Death Syndrome Advisory Council

November 10, 2009

Members of the Council

Thomas G. Keens, M.D.,
Chair. Physician member.

Lorie Gehrke, *Vice Chair.*
SIDS Parent.

Dawn Dailey, R.N., P.H.N.,
Ph.D., *Secretary. Public Health Nurse.*

Kathleen Beichley, *SIDS Parent*

Maureen Chavez, *SIDS Parent*

Steven Durfor, *Police/Fire Department.*

Kathleen Roche, R.N.,
P.H.N., B.S.N., M.S.W.,
Public Health Nurse.

Christina Stanley, M.D.,
Medical Examiner.

Dennis H. Watt, *Coroner.*

Rachel Strickland,
President, Southern Calif. Regional SIDS Council.

Devra Hutchinson,
President, Northern Calif. Regional SIDS Council.

Council Chairperson:

Thomas G. Keens, M.D.
Division of Pediatric Pulmonology
Childrens Hospital Los Angeles
4650 Sunset Boulevard,
Box #83
Los Angeles, California
90027-6062
Phone: 323/361-2101
FAX: 323/361-1355
E-mails:

tkeens@chla.usc.edu
tkeens@gmail.com

Advisory to the



RE: **California SIDS Advisory Council:
November, 2009, Update.**

To Members of the California SIDS Community:

The *California SIDS Advisory Council* was established by California legislation in 1990 to advise the California Department of Public Health on SIDS issues. By law, the *Council* is a nine-member volunteer and interdisciplinary group consisting of SIDS parents, public health nurses, physicians, coroners, and first responders. The goal of the *California SIDS Advisory Council* is to improve SIDS services, education, and research in California.

The most recent meeting of the *California SIDS Advisory Council* was on Monday, October 19, 2009, at 1:00-4:00 p.m., at the California Department of Health Services Building in Sacramento, California. This report summarizes some of the *Council's* activities updated at that meeting.

This nine-member *Council* is only the tip of the iceberg in terms of the hundreds of people who work to improve SIDS services, education, and research in California. Therefore, we need your help, as we are here to help you. In order for the California SIDS community to have access to the activities and actions of the *California SIDS Advisory Council*, we have established a website, which is part of the California SIDS Program website. The purpose of the website is to inform the public about our activities. An important goal of the Council is complete transparency of our activities and actions. It is hoped that this website will provide some of this. The website address is:

<http://www.californiasids.com/Universal/MainPage.cfm?p=120>

The website can also be reached directly by "Googling" *California SIDS Advisory Council*.

The Academy of the California SIDS Advisory Council Membership.

There is much too much to be done in California by only nine people, but we can not expand membership in the *Council* beyond nine by law. Therefore, we have established the *Academy of the California SIDS Advisory Council*, to which those individuals volunteering to help us will be appointed. This will give them public recognition for their service. Current members of the Academy include: *Angel Hopson,*

R.N., M.S.N., M.P.H.; Tommi Gaines, Dr.P.H., M.S.; Henry F. Krous, M.D.; Magali Leialoha; John Margetis; Susan Moore, M.A.; James K. Ribe, M.D.; Danielle Sees, R.N., P.H.N.; Penny Stastny, B.S.N., P.H.N.; and Laura Wiggs. However, membership in the Academy is potentially unlimited when others sign on to work on Council projects.

Disparity in the Consistency of the Diagnosis of Infants Dying Suddenly and Unexpectedly in California.

A longstanding problem in California is a disparity in the consistency of the diagnosis of infants who die suddenly and unexpectedly without an obvious cause. In some jurisdictions, such infants may have a cause of death signed out as "SIDS", in some "Undetermined", in still others "Sudden Unexplained Infant Death", etc. The problem is that infants presenting in the same way with the same findings will have a different diagnosis as cause of death, depending in which county the death occurred. This makes no sense medically or scientifically. Further, it is possible that the diagnosis used to define the cause of death may impact surviving SIDS parents and affect their grieving process. This is a complex problem, which has eluded the *Council* for many years. Yet, this must be addressed in a systematic manner. The *Council* has committed itself to make this issue a priority.

Kathryn Martin, Ph.D., M.P.H., Tommi Gaines, Dr.P.H., and Laura Wiggs at the Southern California Injury Prevention Research Center at UCLA, are conducting a research study on Coroners and Medical Examiners in California. The project hopes to assess how Coroners and Medical Examiners arrive at diagnoses of the causes of death in infants dying suddenly and unexpectedly. The study methodology is a survey, describing a number of death scene investigation and autopsy findings, and asking the Coroners or Medical Examiners to determine cause of death and manner of death. The vignettes provide a variety of scenarios seen in California. The study has been implemented, and results are being analyzed. It is the hope of these investigators that the results of this study will improve investigation and reporting practices within our state. It appears that this study specifically addresses the areas of concern that the *Council* has had for many years. We are hopeful that we can work with *Doctor Kathryn Martin* and her colleagues to utilize this information to improve these services in California.



I have been invited by *Dennis Watt*, President of the California State Coroners' Association (CSCA) and Member of the California SIDS Advisory Council, to attend a meeting of the Executive Board of the CSCA, when they meet in Pismo Beach on March 4, 2010. The purpose of the meeting will be to have an informal conversation about the issues concerning the California SIDS Advisory Council, seeking the help from the CSCA leadership. I am thrilled at this opportunity. I am extremely grateful to *Dennis Watt* for inviting me to meet with CSCA leadership. I am hopeful that we can communicate our respective concerns and develop some plans to address issues.

Impact of the Diagnosis on Parents.

One concern about the increasing use of the “undetermined” diagnosis is the impact of the specific determination of the cause of death on SIDS families, their grieving process, etc. There are a number of published studies on the impact of a SIDS death on parents, their psychological reactions to the death, etc. However, we are not aware of published studies, which address this specific issue. The *California SIDS Advisory Council* believes that the specific diagnosis received *does* have an impact on parents’ grief and road to recovery. SIDS is generally considered to be a biological disorder and a natural manner of death, which implies that parents did nothing to cause the death. According to the SIDS parents participating in *Council* discussions, the SIDS diagnosis helped tremendously to reduce guilt, as these parents could point to this diagnosis as evidence that they did not cause their baby’s death. On the other hand, a diagnosis of “undetermined”, or a similar non-SIDS diagnosis, might taint the baby’s death. If the Coroner could not use the SIDS diagnosis, what did he or she think the parents might have done to cause or contribute to the death? Many SIDS parents believe that the use of a non-SIDS diagnosis complicates grief and recovery.

John Margetis, a USC undergraduate student working with *Doctor Thomas Keens*, and in collaboration with *Dawn Dailey*, *Kathleen Roche*, *Susan Moore*, and *Gwen Edelstein*, is designing a research study in an attempt to identify any effect that the specific diagnosis may have on parent grief. An anonymous questionnaire (using validated instruments, demographic information, and open-ended questions) will be used to attempt to assess if and/or how differing diagnoses affect parent grief. This instrument is in the final stages of being prepared. The study will then undergo Institutional Review Board review and approval (to assure that the rights and welfare of human research subjects are protected). We plan to send this to SIDS parents from the *California SIDS Program* mailing list.

In support of this project, *John Margetis* was the recipient of the *Rose Hills Foundation Fall 2009 Science and Engineering Fellowship* from the University of Southern California.



If a non-SIDS diagnosis is found to complicate grief, this finding may dissuade Coroners from making such diagnoses when medical or scientific evidence is lacking to differentiate.

SIDS Parent Support in California.

SIDS parent support groups in California are struggling. Yet, they are truly a scarce resource, as they provide services to SIDS families that no one else can. Therefore, it is critically important that these SIDS parent support groups remain active and capable of helping others. Some SIDS parent support groups in California have suspended their operations. While others have attempted to step in and provide these services, there are challenges. Some obstacles identified by the *Council* include: serving hard to reach populations, and serving monolingual populations. Some groups are exploring new models of support. It is possible that the traditional face-to-face parent support

meeting appeals to fewer parents in the current era. At the last *Council* meeting, there was discussion of the role of internet or on-line support. It is unclear how the *Council* can help, but this is certainly a priority issue. However, the *Council* remains open as a forum for discussion and brainstorming.

Public Health Nursing Issues.

Recent research shows that very few primary care physicians are providing SIDS risk reduction counseling to new mothers ¹. These findings paralleled those of *Penny Stastny's* research exploring practices in newborn nurseries ². Health care providers continue to need to be educated early about SIDS risk reduction. The *Council* is committed to continuing SIDS Risk Reduction education. However, we need to understand the needs of PHNs and what type of support they would find helpful. The PHN Council Representatives will continue to work with the state program and other PHNs to develop recommendations.

Southern and Northern California Regional SIDS Councils.

The *Southern and Northern California Regional SIDS Councils* are the *California SIDS Advisory Council's* windows on the California SIDS community. The Presidents of each Regional Council are ex-officio members of the *California SIDS Advisory Council*, and they report issues, concerns, and actions of the Regional Councils to the *California SIDS Advisory Council* at each meeting. The best way to have continuing communication and influence on the *California SIDS Advisory Council* is to become active in your respective Regional SIDS Council. I specially encourage SIDS parent support groups to have one or more representatives on the Regional SIDS Councils so that your voices may be heard. Information about the location and time of Regional SIDS Council meetings can be obtained from the *California SIDS Program*, or from:

- Rachel Strickland, President, Southern California Regional SIDS Council:
shawnrachelhuntr@aol.com
- Devra Hutchinson., President, Northern California Regional SIDS Council:
Devra.Hutchinson@acgov.org

The *California SIDS Program*, in conjunction with one of the Regional SIDS Councils (Southern in even years; Northern in odd years), puts on the *Annual California SIDS Conference*. Historically, this conference attracts an audience of SIDS parents and public health nurses with an interest in SIDS. This year, the *2009 Annual California SIDS Conference* was planned by the Northern California Regional SIDS Council, and it was held in Sacramento on Tuesday, October 20, 2009. This conference focused on grief, and it featured a renowned expert in grief, *Darcie Simms*.

Proposed California Child Care Provider Legislation.

Nathan Salomonis, Ph.D. and Heather Myers, R.N., SIDS parents from Northern California, are working with members of the California State Assembly to propose state legislation which would

¹ Eron, N.B., K.M. Dygert, C. Squillace, N.J. Webster, A. Andiranos, E.G. Crockett, and L. Consenstein. The physician's role in reducing SIDS. *Health Promotion Practice*, online first, published July 20, 2009.

² Stastny, P.F., T.Y. Ichinose, S.D. Thayer, R.J. Olson, and T.G. Keens. Infant sleep positioning by nursery staff and mothers in newborn hospital nurseries. *Nursing Research*, 53: 122-129, 2004.

require licensed child care providers in California to be aware of SIDS Risk Reduction Recommendations and to adhere to them when caring for infants under one-year of age. Details of the proposed legislation have not been finalized, and in the current state economic climate, it is not certain that such a bill should be proposed at this time. However, the *California SIDS Advisory Council* is philosophically in agreement with such legislation which would extend SIDS Risk Reduction education and action to Licensed Child Care Providers in California. It is too early to tell how this will go.

Next Council Meeting.

By California law, the meetings of all legislatively mandated Advisory Councils are open to anyone interested. The next meeting of the *California SIDS Advisory Council* will be by telephone conference call on Tuesday, January 26, 2010, at 1:30-3:30 p.m. Details on how to access the teleconference can be obtained from:

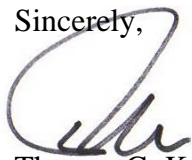
Guey-Shiang Tsay, R.N., M.S.N.
Nurse Consultant III
California Department of Public Health
Phone: (916) 650-0374
Email: Guey-Shiang.Tsay@cdph.ca.gov

The remaining meetings of the *Council* for the coming year will be:

- Telephone conference call on Tuesday, April 27, 2010, at 1:30-3:30 p.m.
- Telephone conference call on Tuesday, July 27, 2010, at 1:30-3:30 p.m.
- In person meeting date to be determined (day prior to the 30th Annual California SIDS Conference in Southern California).

SIDS services and education in California are strong, but they can still be improved. Some problems will require innovative solutions. There are many dedicated individuals in California who are working hard to find solutions. The *California SIDS Advisory Council* serves as a resource to improve SIDS services, education, and research in California.

Sincerely,



Thomas G. Keens, M.D.
Chair, California SIDS Advisory Council.



California SIDS Advisory Council

October, 2009



Kathleen Beichley



Maureen Chavez



Dawn Dailey



Steve Durfor



Lorie Gehrke



Tom Keens



Kathleen Roche



Christina Stanley



Dennis Watt



Rachel Strickland



Devra Hutchinson