



California Sudden Infant Death Syndrome Advisory Council

California SIDS Advisory Council: January, 2012, Update.

Members of the Council

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

Lorie Gehrke, *Vice Chair,*
SIDS Parent.

Kathleen Beichley,
Secretary, SIDS Parent

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

Yolanda DeMello, *SIDS*
Parent

Steven Durfor, *Police/Fire*
First Responder.

James K. Ribe, M.D.,
Medical Examiner.

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

Dennis H. Watt, *Coroner.*

Karen Jackson, P.H.N.,
President, Southern Calif.
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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 sudden infant death syndrome (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.



**California SIDS Advisory Council
Sacramento, California, October 27, 2011**

The most recent meeting of the *California SIDS Advisory Council* was in person on Thursday, October 17, 2011, at 1:00-4:20 p.m., in Sacramento, California. The Minutes of that meeting is available on line at:

<http://www.californiasids.com/UploadedFiles/AdvisoryCouncil/Minutes10-27-11.pdf>

This report updates some of the *Council's* activities since 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 is:

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

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

- **Council Membership.**

Doctor Ron Chapman, the Director of the California Department of Public Health, has appointed *Doctor James K. Ribe* as the Medical Examiner member to the *California SIDS Advisory Council*. *Doctor Ribe* is a Medical Examiner in the Los Angeles County Office of Coroner. He is the pathologist who performs nearly all of the infant autopsies in Los Angeles County. He has been an active member of the Southern California Regional SIDS Council for many years, where he has served as one who has educated us about Coroner and Medical Examiner issues, and who has also worked within the Los Angeles County Office of Coroner as an advocate for families. He replaces *Doctor Christina Stanley*, a productive member of the Council who resigned recently.



- **SIDS Risk Reduction Education.**

American Academy of Pediatrics Revised Recommendations, 2011.

The American Academy of Pediatrics published its revised recommendations for SIDS risk reduction on October 17, 2011 ¹. These recommendations update the previous AAP recommendations published in 2005 ². The new recommendations largely support the 2005 recommendations, but the new ones expand and clarify some issues. The changes were



¹ Moon, R.Y., R.A. Darnall, M.H. Goodstein, and F.R. Hauk. American Academy of Pediatrics Task Force on Sudden Infant Death Syndrome: SIDS and other sleep-related infant deaths: expansion of recommendations for a safe infant sleeping environment. *Pediatrics*, 128: 1030-1039, 2011.

² Kattwinkel, J., F.R. Hauck, M.SE. Keenan, M. Malloy, and R.Y. Moon. . American Academy of Pediatrics Task Force on Sudden Infant Death Syndrome: The changing concept of sudden infant death syndrome: diagnostic and coding shifts, controversies regarding the sleeping environment, and new variables to consider in reducing risk. *Pediatrics*, 116: 1245-1255, 20015.

reviewed by the Council at its October 27, 2011, meeting, and by the principal author, *Doctor Rachel Moon*, at the 31st Annual California Sudden Infant Death Syndrome Conference in Sacramento, on October 28, 2011. The 2011 recommendations include information about unsafe infant sleeping environments in order to prevent deaths due to suffocation, strangulation, or entrapment. This is not to say that SIDS is the same as suffocation, strangulation, or entrapment. However, the goal of the recommendations is to reduce the number of sleep-related infant deaths from any cause. Some infants are dying in unsafe sleeping environments, and it is important to include education to avoid these unsafe sleeping situations.

There is an accompanying Technical Report to the AAP recommendations which details the evidence and scientific basis for these recommendations³. At its October 27, 2011, meeting, the *California SIDS Advisory Council* has officially recommended to the California Department of Public Health, that these new recommendations be the basis of SIDS Risk Reduction and Infant Safe Sleep education and campaigns in California.

Los Angeles County Infant Safe Sleep Campaign.

Los Angeles County Supervisor *Mark Ridley Thomas* became aware of infants dying in unsafe sleeping environments. He initiated the *Los Angeles County Infant Safe Sleep Task Force* on June 14, 2010. There is a great deal of motivation to proceed with an aggressive infant safe sleep education campaign in Los Angeles County. *First Five of California* was awarded a \$1.5-million grant to work with the Task Force on safe infant sleep.

At its most recent meeting was on October 13, 2011, there was considerable discussion about the adversarial relationship that seems to be occurring between infant safe sleep advocates and breastfeeding advocates over the recommendation that bedsharing is unsafe. Many breastfeeding advocates take exception to this recommendation. One member of the Task Force suggested that data indicating the dangers of bedsharing may be incomplete, and that other data exist which do not show this relationship. Thus, a *Bedsharing Study Group* was formed as a small, interdisciplinary working group by the *Los Angeles County Safe Infant Sleep Task Force*. It was charged to review scientific evidence on the benefits and risks of parent-infant bedsharing. Specifically, the American Academy of Pediatrics recommends that infants should roomshare, but not bedshare, during the first year of life. Data from Los Angeles County, and elsewhere, indicate that a majority of infants bedshare with their parents. Thus, many parents are not adhering to a strict “no bedsharing policy”. In the absence of information about how to “safely bedshare”, these parents may use more dangerous sleeping environments. Therefore, the *Bedsharing Study Group* was specifically asked to determine if there were ways to make bedsharing safer, and if this should



COUNTY OF LOS ANGELES
Public Health

³ Moon, R.Y., R.A. Darnall, M.H. Goodstein, and F.R. Hauk. Technical Report: American Academy of Pediatrics Task Force on Sudden Infant Death Syndrome: SIDS and other sleep-related infant deaths: expansion of recommendations for a safe infant sleeping environment. *Pediatrics*, 128: e000, 2011. www.pediatrics.org/cgi/doi/10.1542/peds.2011-2220.

be part of the public education messaging on safe infant sleep. The *Bedsharing Study Group* met in person on November 29, 2011. The group did achieve consensus that roomsharing, but not bedsharing, should remain the primary recommendation. However, it became clear that not all bedsharing is the same. Some bedsharing situations are associated with other risk factors. Thus, similar to other organizations providing guidance on safe infant sleep (i.e., the American Academy of Pediatrics), the *Bedsharing Study Group* provided a list of specific conditions which increase the risk. Many parents choose to bedshare despite this advice, so the Group also suggested that the Task Force consider whether or not to provide educational materials about how to make bedsharing safer by avoiding unsafe sleeping environments often associated with sleeping in an adult bed. The *Bedsharing Study Group's* Report will be presented to the *Los Angeles County Safe Infant Sleep Task Force* at its January 18, 2012, meeting. We have been asked not to share this report until it has been reviewed by the Task Force.

- **SIDS Summit for Coroners and Medical Examiners.**

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.

The *California State Coroners' Association (CSCA)* sponsored a *SIDS Summit* at the West Coast Training Conference, held in Studio City on October 19, 2011. There were 32 participants including coroners and medical examiners from major California counties. They engaged in the discussion of cases, common ground, and differences with enthusiasm. The *SIDS Summit* was summarized in the October 27, 2011, Minutes of the California SIDS Advisory Council, and they will not be repeated here.

It is clear that pathologists and coroners are doing the best job they can to determine the cause of death in these infants. However, the less classical nature of SIDS (due to Back to Sleep) and the availability of more information (due to the uniform autopsy and death scene investigation protocol) have resulted in a disparity in the way diagnoses are made. *Doctor Keens* thought the conference was very successful. It is clear that we do not have consensus on how these diagnoses are made in our state. However, I do not think



Coroners' Curriculum Development Committee
California State Coroners' Association



Coroners are as far apart as one might think. The participants all worked diligently to come up with the best possible diagnosis, but the nature of infants presenting to the coroners is far more complex and less uniform than it once was.

It appears that different diagnoses will remain a reality in California. However, it appears that in the minds of the pathologists, the diagnoses of SIDS, SUID, and undetermined are intended to refer to the same thing. Therefore, it will become the responsibility of the *California SIDS Advisory Council* to educate the California SIDS Community that these diagnoses are the same, and they are not intended to cast blame on SIDS parents.

- **Council's Role in SIDS Parent Support.**



Yolanda DeMello

There is difficulty providing support for SIDS families who do not live near an active SIDS Parent Support organization. Therefore, discussion arose about providing such support on line. *Yolanda DeMello* holds monthly online meetings by Skype and on Facebook with other SIDS parents. She has reached out not only from SIDS parents in her immediate area, but from parents worldwide. She has accommodated the time change for online chat with international parents by reaching out at all hours of the day and night. *Yolanda* indicated that this approach is working well. It is cost effective, and it allows people to communicate in the privacy of their homes. *Yolanda* believes that this allows a first step, and when the SIDS parents are ready to face people, they can then more comfortably attend group support meetings. Parents from all over the country participate in the monthly telephone support group.

- **Public Health Nurse Issues.**

The Advisory Council PHNs have conducted a survey of Coordinators in order to determine current Safe Sleep Outreach Practices and to identify specific needs on the parts of the Coordinators. The California SIDS Program worked collaboratively with the California Department of Public Health (CDPH) Maternal, Child and Adolescent Health (MCAH) Division and State SIDS Advisory Council to send a survey to the SIDS Coordinators for the purpose of identifying strategies to meet the educational and training needs of SIDS Coordinators throughout the State. The results of the survey were discussed in the Minutes of the *Council's* October 27, 2011, meeting, and they will not be repeated here. There is continued work in this area in order to increase support for California's PHN County SIDS Coordinators.



Gwen Edelstein



Kitty Roche

- **32nd Annual California Sudden Infant Death Syndrome Conference.**

The Southern California Regional SIDS Council is beginning to plan the 32nd Annual California SIDS Conference. The Conference will be held at the California Endowment Center in downtown Los Angeles, on Tuesday, October 30, 2012. The keynote speaker will be internationally renowned SIDS researcher, Doctor Hannah Kinney from Harvard University. Doctor Kinney has produced the most exciting SIDS research of the past few decades. Further details of the Conference will be developed over the course of this year.



Hannah Kinney

- **The 2012 International Conference on Stillbirth, SIDS, and Infant Survival.**

The 2012 International Conference on Stillbirth, SIDS, and Infant Survival, sponsored by First Candle and the International Society for the Study and Prevention of Infant Deaths, will be held in Baltimore, Maryland, on October 5-7, 2012. The site of the conference will be the Baltimore Marriott Waterfront Hotel. Information about the conference can be found at its website:

<http://www.firstcandle.org/internationalconference/>

For those who have never attended an international SIDS research conference, they present a rare opportunity to network with SIDS parents, program professionals, and researchers from around the world who are dedicated to improving SIDS support, education, and research. If it is at all possible for you to attend this event, you will be educated and inspired, and you will never forget the experience.

The 2012 International Conference on **STILLBIRTH, SIDS AND INFANT SURVIVAL**

PRESENTED BY FIRST CANDLE Helping Babies Survive & Thrive

- **Council Meetings in 2012.**

The California SIDS Advisory Council traditionally holds four meetings per year. Three are by telephone conference call, and the fourth is in-person the day prior to the California SIDS Conference. The meetings for 2012 will be:

- Telephone Conference Call: Tuesday, January 24, 2012, 1:30-3:30 P.M.
- Telephone Conference Call: Tuesday, May 8, 2012, 1:30-3:30 P.M.
- Telephone Conference Call: Tuesday, August 14, 2012, 1:30-3:30 P.M.
- In-person Meeting: the day before the 32nd Annual California SIDS Conference on Monday, October 29, 2012, 1:00-4:00 P.M., at the California Endowment Center in Los Angeles, California.

By law, meetings of legislatively mandated advisory councils are open to the public. Therefore, anyone interested in participating in California SIDS Advisory Council meetings is welcome and encouraged to attend. For information how to access the telephone conference call meeting, please contact *Guey-Shiang Tsay* at Guey-Shiang.Tsay@cdph.ca.gov

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 Program* continues its high standards for training, education, and services to SIDS families. The *California SIDS Advisory Council* is another resource to improve SIDS services, education, and research in California.



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



California SIDS Advisory Council



Kathleen Beichley Dawn Dailey Yolanda DeMello Steve Durfor Lorie Gehrke Tom Keens



James Ribe Kitty Roche Dennis Watt Karen Jackson Aline Armstrong

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

**SAVE
THE
DATE**



The 2012 International Conference on
STILLBIRTH, SIDS AND INFANT SURVIVAL
PRESENTED BY FIRST CANDLE

Mark your calendar to join First Candle as we convene an international group of researchers, health professionals and parent leaders to share concerns and develop strategies to address issues related to perinatal and infant survival.

October 5-7, 2012
Baltimore, MD USA
Baltimore Marriott Waterfront

In Conjunction with the Annual
Meetings of ISA and ISPID

For more information contact IC2012@firstcandle.com or visit www.firstcandle.org.

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