



California Sudden Infant Death Syndrome Advisory Council

May 12, 2011

Members of the Council

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

Lorie Gehrke, *Vice Chair,*
SIDS Parent.

Kathleen Beichley,
Secretary, SIDS Parent

Maureen Chavez, *SIDS*
Parent

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

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.*

Karen Jackson, P.H.N.,
President, Southern Calif.
Regional SIDS Council.

Aline Armstrong, P.H.N.,
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Advisory to the



California SIDS Advisory Council: May, 2011, 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 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.

The most recent meeting of the *California SIDS Advisory Council* was on Tuesday, May 10, 2011, at 1:30-3:30 p.m., by telephone conference call. 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*.

SIDS Risk Reduction Education.

Recent research shows that very few primary care physicians are providing SIDS risk reduction counseling to new mothers¹. These findings paralleled those of *Penny Stastny’s* research exploring practices in newborn nurseries². Further, there is preliminary evidence that prone sleeping rates may be starting to increase again in the U.S.³. Finally, the number of SIDS deaths in California increased in 2007 and 2008. Are these increases related to decreased attention to educating the public about SIDS risk reduction recommendations? The *Council* is committed to continuing SIDS Risk Reduction education.

California Child Injury Prevention Program: Safe Infant Sleep.

Steve Wirtz and *Rachel Zerbo*, Safe and Active Communities (SAC) Branch of the California Department of Public Health (CDPH), are involved with trying to prevent intentional and unintentional injury to children. They received a CDC grant to address three key areas of childhood injury; one of which is Infant Unsafe Sleeping conditions. Their focus is on policy implementation to decrease infant unsafe sleep in California⁴.



SAC Branch has convened a policy action team to work on implementing at least one of the Safe Sleep policy recommendations identified from the earlier planning process.

Tom Keens (California SIDS Advisory Council), and *Gwen Edelstein* (California SIDS Program) are members. The action team held its first teleconference on March 29, 2011; and a second one on May 3, 2011.

Workgroup co-chairs are *Gwen Edelstein*, *Steve Wirtz*, and *Rachel Zerbo*.

Members for the Policy Workgroup were recruited in February and March, 2011, including representatives from California SIDS Council, California Dept. of Public Health, SafeKids California, Department of Social Services, California Hospital Association, California Emergency Medical Services Authority, local Child Death Review Teams, a SIDS Parent, a wonderful volunteer (*Penny Stastny*), and County SIDS Coordinators.

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.

³ Colson, E.R., D. Rybin, L.A. Smith, T. Colton, G. Lister, and M.J. Corwin. Trends and factors associated with infant sleeping position: The National Infant Sleep Position Study 1993-2007. *Arch. Pediatr. Adolesc. Med.*, 163: 1222-1228, 2009.

⁴ Contact information: Steve Wirtz Email: steve.wirtz@cdph.ca.gov
Rachel Zerbo E-mail: Rachel.Zerbo@cdph.ca.gov

- Meetings via teleconference were held 03/29/2011 and 05/03/2011, facilitated by Gwen and Rachel.
- During the initial meeting, group members shared their current organizational interests around safe sleep, reviewed recommendations contained in California Childhood Injury Prevention Policy Plan developed by CDPH-led team, chose initial policy priorities from the plan, and suggested additional individuals to invite to join group.
- During the 05/03/2011 meeting, the workgroup developed action items to support policy priorities.
- The next workgroup meeting will be the first week in June, 2011.
- Workgroup Policy Priorities include:
 - Initiate safe sleep asset mapping for existing county and regional safe sleeping programs and training providers.
 - Formalize resource list of high-quality safe sleeping educational tools, focusing on child care and hospital audience.
 - Information on both of the above will be captured through a state-wide on-line survey.
 - Increase the capacity of local Child Death Review Teams (CDRT) to use standardized reporting forms, with quality control reviews and support for local capacity building.
 - Work with hospitals, birthing centers, and hospital oversight bodies to establish consistent written policies on safe sleeping, both in terms of education for parents and as institutional model practices. Initial plans for achieving this goal include providing support for local safe sleeping stakeholders to advocate for these policies through the development of a toolkit.
 - Explore strategies to expand safe sleeping education for licensed infant care center staff and in-home childcare providers under California Government Code, Title 22. Training Standards for Child Care Providers. This would include identifying potential resources to support the continued distribution of National Institute of Child Health and Human Development's Back to Sleep Campaign materials and updating the Child Care Provider Preventive Health and Safety module with the most current safe sleeping information.
- Safe Sleep Policy Workgroup meeting notes are available to those who would like additional information.
- Other activities include:
 - We are still on hold for the release of Kids Plates grants (that included some safe sleep proposals) due to complex administrative issues of contract authority.
 - *Steve Wirtz* attended the CDC-HRSA-NCCDR sponsored "National Meeting of State CDR Program Coordinators To Enhance the Reviews of Sudden and Unexplained Infant Deaths and the CDR Review Process" in Atlanta, Georgia, on April 18-20, 2011. I learned that CDC's SUID Case Registry 7-State Pilot program has already demonstrated in its 1st year the ability of CDR teams to collect detailed, complete and very timely (within 90 days of death) information on the circumstances surrounding SUIDs using the revised National

Center for CDR's Case Reporting Form (v2.2S). The data will be used to improve investigations, services & prevention activities. Our state's FCANS Program is exploring the possibility of several counties in California using this form as well.

Los Angeles County Infant Safe Sleep Campaign.

Los Angeles County Supervisor *Ridley Scott Thomas* became aware of infants dying in unsafe sleeping environments. He initiated the *Los Angeles County Infant Safe Sleep Task Force* at a meeting 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.

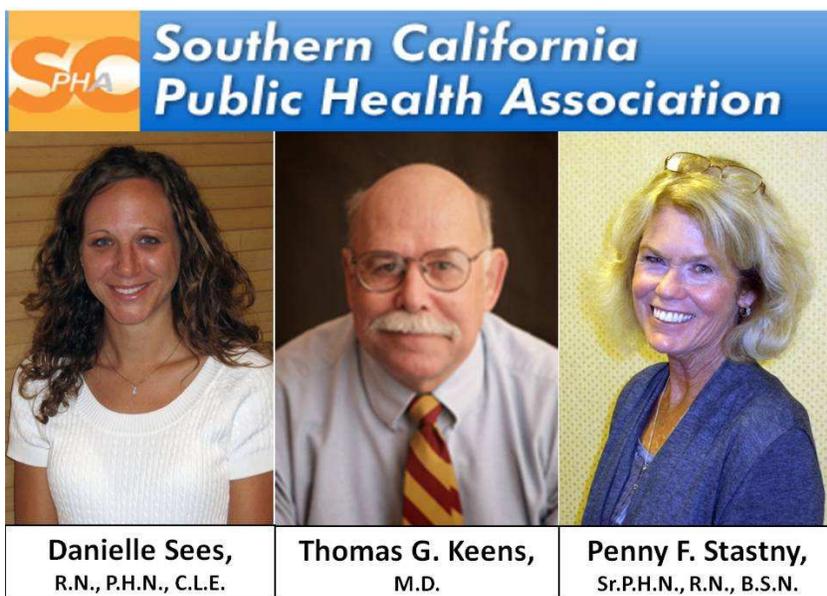
A *Safe Infant Sleep Community Forum* was held in South Central Los Angeles. This was very well received by the community, as members indicated that they did not know this information. The Task Force plans to implement more of these sessions.

Funding from *First Five of California* is in jeopardy. This partly reflects the overall budget situation in California. The Task Force is hopeful that the funds will eventually be awarded, but details are lacking.

Long Beach Safe Sleep for Infants Conference, May 24, 2011.

The Nursing Section of the Southern California Public Health Association is sponsoring a half-day conference entitled, *Safe Sleep for Infants: New Data on Bedsharing and Increased Infant Deaths*. The conference will be held on Tuesday, May 24, 2011, from 9:00 A.M. until noon, at the Miller Children's Hospital at Long Beach Memorial Medical Center. The conference will feature:

- **Danielle Sees, R.N., P.H.N., C.L.E.** SIDS Coordinator. Department of Health and Human Services, City of Long Beach.
- **Thomas G. Keens, M.D.** Chair, California SIDS Advisory Council; Professor of Pediatrics, Physiology and Biophysics, Keck School of Medicine of the University of Southern California; Division of Pediatric Pulmonology, Children's Hospital Los Angeles.
- **Penny F. Stastny, R.N., Sr.P.H.N., B.S.N.** Retired SIDS Coordinator, Los Angeles Department of Public Health, and Orange County Health Care Agency.



This 3-hour conference is designed to update and improve awareness of infant safe sleeping practices. The presenters will discuss unsafe infant sleeping conditions, sudden infant death syndrome (SIDS), sudden unexpected infant deaths (SUID), and unintentional infant deaths. The

Registration Fee is \$10, which includes breakfast and all materials. A Registration Form is appended.

Disparities in the Accuracy and Consistency of SIDS, Undetermined, or SUID Diagnoses.

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. 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.

SIDS Summit for Coroners and Medical Examiners.

The California State Coroners' Association (CSCA) will sponsor a *SIDS Summit* at the West Coast Forensic Science Seminar, to be held in Studio City in late October, 2011⁵. The West Coast Forensic Science Seminar is a 3-day Seminar held annually by the Los Angeles County Department of Coroner. The *SIDS Summit* will be an 8-hour course for forensic pathologists and coroner investigators in California to address the disparity in the diagnosis of the cause of death in infants following a sudden and unexpected death. The problem to be addressed is the inconsistency in how infants are diagnosed. We hope to make a scientific appeal that there should be consistency in the way similar infants are diagnosed. This conference will present background information on SIDS and the diagnosis of the cause of death in infants dying suddenly and unexpectedly. However, the most important part of the Seminar will be a facilitated discussion, where we hope to air all views on this issue, and then attempt to generate enthusiasm to develop a uniform approach to the diagnosis of these infants in California.



In 1974, the Federal and California governments defined a group of babies who died suddenly and unexpectedly, and in whom no cause of death was found at autopsy, as *sudden infant death syndrome (SIDS)*. This resulted in many babies being classified as SIDS deaths, which prompted research into the epidemiology, risk factors, and causes of SIDS. In California, the Boatwright legislation (1991) mandated the use of a uniform autopsy and death scene investigation protocol by all California coroners when an infant was suspected of dying from SIDS. The purpose of the uniform autopsy and death scene investigation protocols was to improve the accuracy of the diagnoses of the causes of death in these infants.

At the same time, the nature of SIDS babies changed as the *Back to Sleep* and *SIDS Risk Reduction* public education campaigns successfully decreased the number of babies dying from SIDS from 1994 to the present. SIDS infants now are much less classical than they were two-decades ago.

⁵ Date not definite. Probably October 20, 2011. This is a meeting for California Coroners and Medical Examiners by invitation only. It is not open to the public.

Now, few babies lack risk factors for SIDS. They are now much more likely to have risk factors, such as prone sleeping, unsafe sleeping surfaces, overheating, exposure to tobacco or other substances, etc. Thus, the cause of death is not as clear or uncomplicated as it once was.

Further, use of the uniform autopsy and death scene investigation protocols gives pathologists more information than they previously had. Therefore, pathologists now have more information to consider when formulating a cause and manner of death. In combination with the less classical nature of current SIDS victims, many pathologists are not as comfortable using the diagnosis of SIDS, and diagnoses like “undetermined” are more commonly used.

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 and the availability of more information have resulted in a disparity in the way diagnoses are made.



Goals of the SIDS Summit: We hope to gather coroners and pathologists from around California to address the diagnosis of infants who die suddenly and unexpectedly. The goals of the seminar are:

- To provide background to the problem of inconstant diagnoses in California of infants dying suddenly and unexpectedly.
- To permit coroners and pathologists to discuss their varying views on this topic.
- To create an awareness among California coroners and pathologists that infants are inconsistently diagnosed in California, even when death scene, autopsy, and clinical history findings are identical.
- To move toward achieving a consensus on how these babies should be diagnosed.

The *SIDS Summit* will be an 8-hour course within the 3-day (24-hour) *West Coast Forensic Science Seminar*, annually hosted by the Los Angeles County Department of Coroner. This Seminar already attracts many coroners and pathologists from California.

At the Council meeting, *Tom Keens* invited discussion on the following issue: Suppose hypothetically that the SIDS Summit is a success, and that California Coroners and Medical Examiners agree to diagnose all infants the same, but that they choose the term “Undetermined” or “Sudden Unexplained Infant Death (SUID)”. What would be the reaction of the California SIDS Community? SIDS parents indicated that they like the SIDS diagnosis, as it implies a natural death which parents did not cause. There was considerable discussion on this issue. There is a good possibility that if some consensus is achieved, “SIDS” will not be the chosen diagnosis. There may be legal implications, as current California laws require death scenes and autopsy protocols for suspected “SIDS”, and failure to use this diagnosis may get one out of the law. The California SIDS Program is funded as a program to address SIDS, not SUID. Would a change in the name have implications for funding of this program, research, educational programs, etc.? Most people

on the call seemed to prefer that “SIDS” be retained. However, there was also a sense that achieving some consistency in the diagnosis of these infants (even if the diagnosis is not “SIDS”) is desirable. This issue was not settled.

Stanislaus County Infant Safe Sleep Campaign.



In 2007, the Stanislaus Sheriff Coroner investigated 18 infant deaths. Fourteen died in unsafe infant sleeping environments. In response, the Stanislaus County Sheriff Coroner and Public Health Department launched an infant safe sleep campaign. They obtained grant funding from *First Five of California*, and they produced a video as well as other activities. The number of babies dying in Stanislaus County dropped dramatically



Kristi Ah-You
Stanislaus Sheriff-Coroner

following the campaign. The video is available on line:

<http://www.schsa.org/PublicHealth/pages/safesleep/index.html>

The Stanislaus County Sheriff Coroner *Kristi Ah You* and her colleagues demonstrate a great example of how Coroners can discover a problem causing increased deaths and take action to reduce those deaths.

Council's Role in SIDS Parent Support.

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. *Colleen Ma*, SIDS parent from Orange County, suggested using a platform called *MyFamily.com*. This is a versatile platform, which allows on-line discussion, chat, photos, blogs, etc., at a very reasonable price. Subsequently, she established the site for the California SIDS Community, called the *California SIDS Parent Support Group*. Interested persons can join the group, but only group members will see any information posted.

Public Health Nurse Issues.

SIDS Coordinators in California generally agree that an annual meeting for support and education would be helpful. *Gwen Edelstein* and *Kitty Roche* are developing a quick survey for SIDS Coordinators to determine how to best meet their needs especially since many have been newly appointed to their position. Possibilities include: adding a special session on to the SIDS Conference, or doing a Web Cast. Alternate options must stay within State guidelines.

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:

- *Karen Jackson, P.H.N.*, President, Southern California Regional SIDS Council:
KJackson@ochca.com
- *Aline Armstrong, P.H.N.*, President, Northern California Regional SIDS Council:
Aline.Armstrong@sfdph.org

Southern California Regional SIDS Council.

Karen Jackson, P.H.N., President of the Southern California Regional SIDS Council, reported on the activities of the Southern California Regional SIDS Council. The Council is preliminarily beginning to think about the 2012 California SIDS Conference.

Northern California Regional SIDS Council.

Aline Armstrong, P.H.N., President of the Northern California Regional SIDS Council, reported on the activities of the Northern California Regional SIDS Council. The main activity is planning the *31st Annual California SIDS Conference*, hosted by the Northern California Regional SIDS Council, which will be held on Friday, October 28, 2011, at the California Department of Health Services East End Complex, located at 1500 Capitol Avenue, Sacramento, California. The featured speaker will be renowned SIDS researcher, *Doctor Rachel Moon*, Professor of Pediatrics, George Washington University School of Medicine and Health Sciences, and Children's National Medical Center in Washington, D.C. Her research has focused on improving safe infant sleep and SIDS Risk Reduction education to the public. She has highlighted areas of priority, where more work is needed, and the results of successful educational campaigns. The *California SIDS Program* puts on this conference each year.



Rachel Moon. M.D.

On Thursday, October 27, 2011, 1:00-4:00 P.M., the *California SIDS Advisory Council* meeting will be held at this location as well. By law, meetings of legislated advisory councils to state agencies are open to the public. All interested persons are welcome to attend.

Lorie Gehrke, President of the SIDS Alliance of Northern California, will host a Welcome Reception on Thursday, October 27, 2011, at the Hyatt Hotel in Sacramento following the Council meeting. More details will be forthcoming at a later date. The *California SIDS Program* is working with the Hyatt Hotel Sacramento located at 1209 L. Street to obtain a block of rooms at the State rate of \$84 single/double occupancy.

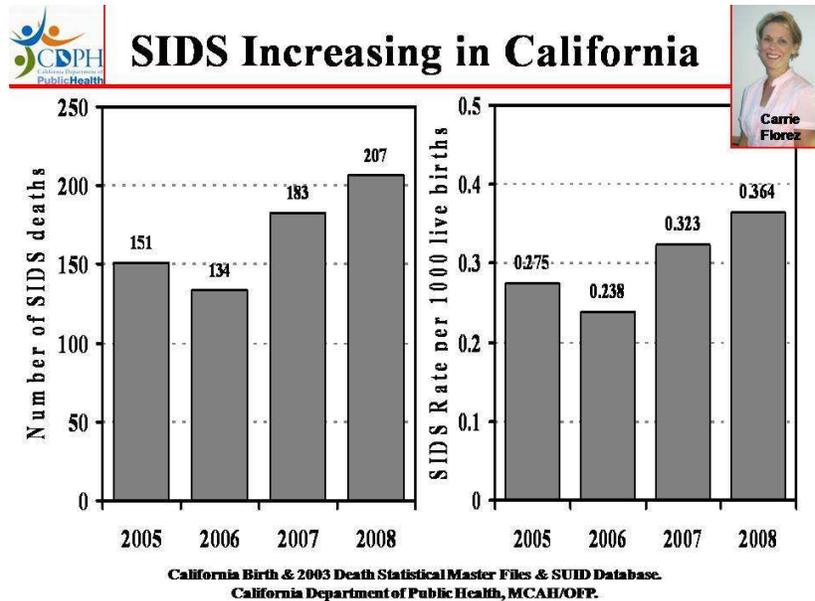
State Report.

Guey-Shinag Tsay reported the following:

- *Governor Brown* issued the Executive Order regarding state employee travel on April 26, 2011, to limit both in-state and out-of-state travel to those trips that are mission critical or at no cost to

the State. This may affect reimbursement for Council members to the 31st Annual California SIDS Conference.

- Updated change in California Department of Public Health (CDPH) Administration: *Doctor Mark Horton*, Director of CDPH left his position and *Doctor Howard Baker* served as Interim Director of CDPH effective March 1, 2011.
- MCAH received the third and final Federal guidelines for Home Visiting Program on February 8, 2011, and it is working on the submission of an updated state plan due within 3-4 months, which is between May 9, 2011, to June 8, 2011.
- *Dr. Connie Mitchell*, *Carrie Florez* and I had a conference call with *Angel Hopson* (SIDS Coordinator from Los Angeles) and *Doctor James Ribe* (LA Medical Examiner) in March, 2011. We gained some insight as to why SIDS deaths are rising in Los Angeles. We are also going to have a conference call with *Kitty Roche* and *Doctor Christina Stanley* for issues related to SIDS in San Diego next week.
- The Northern California SIDS Training for Emergency Personnel and Public Health Professionals in San Jose on April 7, 2011, was very successful. All of the people including the speakers and SIDS parents participating in this training were great. Big thanks to *Gwen Edelstein*, *Cheryl McBride*, and *Teresa Folan* for their hard work.
- *Carrie Florez* is not able to participate on the conference call today. She is working on the 2009 CDPH SIDS fact sheets.



California SIDS Program Report.

Gwen Edelstein submitted a detailed written report of California SIDS Program activities for January 1 – March 31, 2011, that was distributed to all Council members.

The California SIDS Program held two SIDS Trainings for Public Health Nurses and Emergency Responders in Ventura on January 27, 2011, and in San Jose on April 7, 2011. Registrants include Chaplains (who have enrolled for the first time), sheriff/coroners, fire fighters, EMT's, and public health professionals, with several counties represented in enrollment.

Cheryl McBride stated there were 216 presumptive SIDS cases reported to the California SIDS Program for 2010, and 45 presumptive SIDS cases reported



for 2011. Compliance for 2011 for submission of Coroner Notification Cards is 89%, and 64% for Public Health Services Reports forms. Quarterly compliance letters were mailed March 30, 2011, to all counties delinquent with submission of the State Coroner Notification Cards and Public Health Services Report forms for 2010 and 2011.

Council Meetings for 2011.

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 afternoon, August 9, 2011, at 1:30-3:30 p.m.. Contact Guey-Shiang Tsay, R.N., M.S.N. (Guey-Shiang.Tsay@cdph.ca.gov) for information how to access the call.

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.

California SIDS Advisory Council



Kathleen Beichley



Maureen Chavez



Dawn Dailey



Steve Durfor



Lorie Gehrke



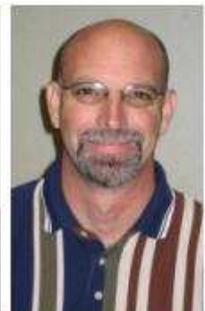
Tom Keens



Kathleen Roche



Christina Stanley



Dennis Watt



Karen Jackson



Aline Armstrong

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



Safe Sleep for Infants: New Data on Bedsharing & Increased Infant Deaths

Speakers

Thomas G. Keens, MD, Professor of Pediatrics, Physiology and Biophysics, Keck School of Medicine USC, Division of Pediatric Pulmonology Children's Hospital Los Angeles

Penny Stastny, RN, PHN, Retired SIDS Coordinator Los Angeles County Department of Public Health, Orange County Health Care Agency

Danielle Sees, RN, PHN, CLE, SIDS Coordinator City of Long Beach Department of Health and Human Services



**Tuesday, May 24, 2011
9:00 am – 12:00 pm**

**Long Beach Memorial Medical Center
Houssel's Forum
2801 Atlantic Avenue
Long Beach, CA 90806**

This 3 hour conference is designed to update and improve awareness of infant safe sleep practices. The presenters will discuss unsafe sleeping habits, Sudden Infant Death Syndrome (SIDS), Sudden Unexpected Infant Deaths (SUIDs) and unintentional infant deaths.

After attending this conference participants will be able to:

Verbalize the safe sleep and risk reduction practices for infants.

List one way to implement the AB757 State Statute that requires hospitals to provide safe sleeping education to all new parents.

Verbalize the importance of teaching breastfeeding mothers how to maintain a safe and separate sleeping space during sleep hours.



Southern California Public Health Association (a 501c3)
An Affiliate of the American Public Health Association

**Safe Sleep for Infants:
New Data on Bedsharing & Increased Infant Deaths**
Tuesday, May 24, 2011 • 9:00 AM to 12:00 PM
Long Beach Memorial Medical Center ~ Houssel's Forum
2801 Atlantic Ave., Long Beach, CA 90806

Name: _____

Mailing Address: _____

Email Address: _____

Registration Fee: \$10.00 *includes breakfast and all materials

Are you a current member of SCPHA? Yes No

Are you interested in becoming a member of the SCPHA Nursing Section?

Yes No

Continuing Education Units:

LCSW # _____ RN # _____

**Please mail completed registration form and check to
SCPHA, PO Box 92453, Long Beach, CA 90809**

Space is Limited, Please Register by Friday, May 13, 2011

* A 10% administrative fee will be charged to any cancellation prior to 5/6/2011. After 5/6/2011, transfers only.

Southern California Public Health Association – SCPHA
PO Box 92453 Long Beach, CA 90809•
www.SCPHA.org Email: info@scpha.org