



California Sudden Infant Death Syndrome Advisory Council

Minutes of the August 14, 2012, Meeting

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,
M.S.P.M., *SIDS Parent.*

Steven Durfor, *Police/Fire*
Department.

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

Kitty 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.
Regional SIDS Council.

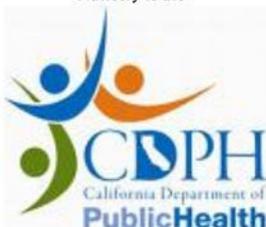
Aline Armstrong, P.H.N.,
President, Northern Calif.
Regional SIDS Council.

Council Chairperson:

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Advisory to the



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

- **Members Present:** Thomas G. Keens, M.D., *Chair*; Lorie Gehrke, *Vice Chair*; Kathleen Beichley, *Secretary*; Aline Armstrong, P.H.N.; Dawn Dailey, RN, PHN, PhD; Steven Durfor; Karen Jackson, P.H.N.; James K. Ribe, M.D.; and Kitty Roche, RN, PHN, BSN, MSW.
- **Members Absent:** Yolanda DeMello, M.S.P.M.; and Dennis Watt.
- **State and California SIDS Program:** Gwen Edelstein, RN, PNP, MPA; Carrie Florez; Cheryl McBride, RN; and Guey-Shiang Tsay, RN, MSN.
- **Guests:** Lidia Escobar, L.C.S.W.; Catherine Farnham, R.N., P.H.N.; Angel Hopson, R.N., M.S.N., P.H.N.; Danielle Sees, R.N., P.H.N., C.L.E.; Jessica B. Spearman; Penny Stastny, R.N., B.S.N., Sr. P.H.N.; and Deanne Tilton.
- The meeting was held by telephone conference call. The meeting was called to order at 1:30 P.M., on Tuesday, August 14, 2012.

- **Introductions.**

Council members, state staff, and guests introduced themselves.

- **SIDS Risk Reduction Education.**

California SIDS Program: Updates with new 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 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. These recommendations were reviewed in more detail at the Council's October 27, 2011, meeting. For details, please see the Minutes of the October 27, 2011, meeting at <http://www.californiasids.com/Universal/MainPage.cfm?p=122>



At its October 27, 2011, meeting, the *California SIDS Advisory Council* 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. A handout, *Safe Sleep Environments for Infants: Reducing the Risk of SIDS and Other Sleep Related Infant Deaths* was developed by the California SIDS Program. The California SIDS Advisory Council recommended that this document be approved by CDPH MCAH as a tool for health care professionals providing SIDS risk reduction and safe sleep educational interventions.

Gwen Edelstein shared that the new handout is posted on the California SIDS Program website replacing the Safe Sleep Top Ten messages and is available as a PDF to download and disseminate along with the published 2011 AAP Policy Statement and Technical Report. The AAP research articles and revised educational SIDS risk reduction/safe sleep recommendations were mailed to all SIDS Coordinators in June 2012 for inclusion in *the SIDS Handbook for Public Health Professionals*. At the SIDS Trainings for Emergency Personnel/Public Health Professionals conducted by the California SIDS Program on March 22 and June 7, 2012, the new recommendations were incorporated into the training curriculum. As new educational resources become available they will be added to the Program's website.

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.S.E. 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, 2005.

Gwen stated she had recently contacted the National Institute of Child Health and Development (NICHD) National Back to Sleep Campaign office to check on the status of new safe sleep materials. However, they have not yet responded to her inquiry. In the interim, the current NICHD Back to Sleep Campaign materials with the Safe Sleep Top Ten messages will continue to be used for educational outreach activities.

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. *First Five Los Angeles* was awarded a \$1.5-million grant to work with the *Task Force* on safe infant sleep. *Deanne Tilton*, ICAN Executive Director in Los Angeles County, and *Jessica Spearman*, Program Director of the Los Angeles County Infant Safe Sleep Task Force, summarized the activities of the *Los Angeles County Infant Safe Sleep Task Force*.

The Infant Safe Sleeping Campaign has spent the second quarter of 2012 planning and conducting focus groups and community forums for the Los Angeles County Infant Safe Sleeping Campaign.

Focus groups, highlighting our target audiences, were completed by the end of May, 2012. ICAN Associates and First 5 LA have collaborated with social marketing agency, Rogers Finn Partners, to determine focus groups demographics, agree on recruitment strategy and participant questionnaire, as well as developing focus group agendas and concepts to be tested. Three focus groups were conducted consisting of audiences of African-American Mothers and Grandmothers (not related), Latina Mothers-English Speaking and Latina Mothers-Spanish speaking. Key findings from the focus groups will influence the campaign message and tactical outreach. Each focus group ran approximately 2-hours in length and consisted of discussion, testing key concepts (taglines), and viewing PSAs. Key findings included the participants' desire for a direct message, an explicit message, and a message told through a story. Findings also highlighted the Los Angeles County Coroner as a trusted source to relay the message of infant safe sleeping to audiences.

Community forum preparation has continued with the first forums conducted during the summer of 2012. Community forums serve to educate audiences, both community members and professionals, about infant safe sleeping. Forums also serve as an opportunity to begin the conversation of infant safe sleeping to create familiarity with the issue for when the campaign and media push roll out in 2013.

The campaign will join pre-existing meetings (parenting classes, mommy and me classes, monthly meetings, staff meetings) to present to audiences about infant safe sleeping and create buy-in for each audience. Forum structure and materials will be tailored to each audience type (English/Spanish speaking audiences, parent and caregiver audiences, and audiences of professionals).



COUNTY OF LOS ANGELES
Public Health

The campaign organized a community forum for 170 community agency providers on July 31, 2012, at the California Endowment Center. The forum included a presentation from Dr. James Ribe, Senior Deputy Medical Examiner, Los Angeles County Coroner, where he gave a comprehensive PowerPoint presentation on Infant Safe Sleeping. The forum inspired over 80 requests for additional infant safe sleep presentations and additional infant safe sleep materials (2000 pamphlets and 115 training DVDs were requested).

Members of the Infant Safe Sleeping Task Force have been contacted as well as 12 Community Child Abuse Council Chairpersons requesting aid in community forum preparation. The campaign has also reached out to agencies that service families to help schedule forums.

ICAN Associates has made the Denise Bertone, Carol Berkowitz training video, "A Space of My Own: Reducing Sleep-Related Infant Deaths in LA County," highlighting infant safe sleeping and abusive head trauma available for viewing on their website, www.ican4kids.org/safesleep. Additionally, viewers can request copies of the training video and safe sleep pamphlets.

ICAN Associates, social marketing agency, Rogers Finn Partners, and Partner First 5 LA are currently finalizing details for the campaign's pilot program. The pilot program will work with Supervisor Mark Ridley-Thomas' office to saturate a community with infant safe sleep information for a duration of time. The pilot program will serve as a test run for materials, tactical outreach, and collaboration with stakeholder agencies.

The remaining quarters of 2012 will not only focus on conducting community forums, rolling out the pilot program but also developing trainings for county agencies. ICAN Associates First 5 LA and Rogers Finn Partners will also finalize campaign materials, tactical outreach and strategy during the end of this first development year.

Preventing Unsafe Infant Sleep Workgroup

Steve Wirtz, Ph.D., Chief, Violent Injury Surveillance Unit, SAC Branch, CDPH, was unable to participate on the conference call but submitted a brief update. He noted that they have integrated their SAC Branch efforts on the child care arena into the broader group which is focused on developing new regulations for Department of Social Services (DSS) Community Care Licensing. In addition, CDPH SAC Branch is continuing their group efforts to work on hospital safe sleep policies and practices. *Stephanie Biegler*, Deputy Director Child Abuse Prevention Council of Sacramento, is helping with the facilitation and functioning of this group. *Steve* indicated that "We will keep you informed as we make progress."

Gwen Edelstein provided a further update of the CDPH Safe and Active Communities (SAC) Branch Workgroup activities.

- On May 21, 2012, the CDPH SAC Safe Sleep Policy Workgroup led by *Rachel Zerbo* conducted a teleconference. *Gwen* updated members on the California SIDS Program risk reduction/safe sleep activities, and *Angel Hopson* reported on the LA County Infant Safe Sleep Task Force. Workgroup members discussed the need for hospital safe sleep policies and strategies for education to staff and parents of newborns. It was noted that some successful projects are already in place which need to be identified along with teaching videos. *Rachel Zerbo* led a discussion on safe sleep assets mapping which could include an online survey sent to "safe sleep stakeholders". The survey would look at what resources

agencies are currently using for education, what types of outreach is being provided and what is being done to implement safe sleep policies.

- The major focus, as per *Steve Wirtz's* report, has been safe sleep activities targeted at DSS licensed child care centers. A Health and Safety Regulatory Workgroup is being led by *Mary Beth Phillips, PhD*, California Military Child Care Liaison, who is funded by the Department of Defense. Other members include *Lucy Chaidez*, California Emergency Medical Services Agency, and *Nathan Salomonis*, SIDS Parent. This workgroup met with staff from DSS Community Care Licensing on June 1st in Sacramento. *Nathan Salomonis* presented a draft safe sleep proposal and rubric for regulatory reform which included evidence based research and reports to support the revised safe sleep practices. The workgroup is proposing revisions to the regulations for licensed child care centers so they exemplify the current AAP safe sleep recommendations including educational materials to meet the mandates of AB757. A teleconference took place on July 17th, to continue work on drafting DSS CCL safe sleep guidelines, and identifying strategies and resources for educating licensed child care center staff. The Health and Safety Regulatory Workgroup is planning to meet with DSS CCL again on September 18, 2012.

Infant Safe Sleep at Children's Hospital Los Angeles:

While the Council Chair extols the virtues of Children's Hospital Los Angeles (CHLA; and, of course, USC), no hospital is entirely perfect. Even CHLA can improve in some areas. Two first year pediatric residents, *Doctors Sandy Gildersleeve and Manu Raam*, are embarking upon a 3-year project to improve safe infant sleeping conditions for inpatients at CHLA, and to improve parent education on safe infant sleep both for infants discharged from the hospital and for infants seen in our outpatient clinics.

CHLA Pediatric Residents can choose an *Advocacy Track* in their residency. This provides them with the opportunity to design and implement a QI/QA and/or research project to improve some area of pediatric care. *Doctor Gildersleeve and Raam* have chosen this important area. Details of the actual project remain to be developed.

One of the CHLA nurses on 5-East, *Myrel Catbagan*, has also been working to improve safe infant sleep on her ward at CHLA. She will be joining this larger project, as her enthusiasm will be helpful, especially to enlist to support of nurses in the hospital.



Dr. Sandy Gildersleeve Dr. Manu Raam

- **SIDS, Undetermined, or SUID Diagnoses.**

Educating the SIDS Community in light of *SIDS Summit 2011*.

In California, there has long been 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 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. For details, please see the Minutes of the October 27, 2011, meeting at <http://www.californiasids.com/Universal/MainPage.cfm?p=122>

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. Thus, 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.



Dr. Keens and Gwen Edelstein developed a document to explain the shift in diagnosis whereby SIDS, SUID and undetermined are used interchangeably. The document includes the following:

Coroners Should Send the Names of All Sudden Unexpected Infant Deaths to their County Public Health Nurses so the Families can Receive Services.

A consequence of babies receiving different causes of death in California is that families may not receive education and grief support services depending on the diagnosed cause of death. The first step to insure that all families receive these services is for the Coroners to inform the County Public Health Nurses of the families of all infants who die suddenly and unexpectedly, regardless of the diagnosis. *Doctor Keens* will work with *Dennis Watt*, former President of the California State Coroners' Association, to begin planning a way to encourage all California Coroners to do this.

County Public Health Departments Should make Public Health Nurse Visits to the Families of all Infants Dying Suddenly and Unexpectedly Regardless of the Diagnosed Cause of Death.

A consequence of using different diagnoses for infants dying suddenly is that not all counties may provide Public Health Nurse visits. California legislation requires that the local health jurisdiction Public Health SIDS Professional make contact to provide education and grief support to families of babies dying from SIDS. However, families of infants with diagnoses other than SIDS (Undetermined, SUID, etc.) are not specifically covered under the law. The *California SIDS Advisory Council* strongly believes that families of all infants dying suddenly and unexpectedly should receive these essential services.

A draft document was circulated to Council members. After review and discussion, the following motion was made, seconded, and passed unanimously: "The Council recommends that its new policy, "Diagnosing the Cause of Death for Infants Dying Suddenly and Unexpectedly", approved 08/14/2012, be transmitted to the California Department of Public Health's (CDPH) Maternal, Child & Adolescent Health (MCAH) Policy Branch for consideration to enact as CDPH policy and disseminate through all Public Health local health jurisdictions (LHJs)." A copy of the document entitled, *Diagnosing the Cause of Death for Infants Dying Suddenly and Unexpectedly*, is appended to these Minutes.

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

Representatives from three parent support groups in San Diego County will be meeting on August 15, 2012, with the six SIDS PHNs and the SIDS Coordinator to give a profile of their bereavement approach and support.

Gwen Edelstein reported that the California SIDS Program conducted two Peer Contact Trainings in Fiscal Year 2011/2012 in response to the need for more parents/family members trained to support newly bereaved families throughout the State. In Los Angeles on January 17th, four parents and one grandparent were trained; and on April 20th, in Walnut Creek eight parents participated in the training. These newly trained SIDS peer contacts were added to the list of current peers maintained by the Program; the listing was distributed to all SIDS Coordinators in June 2012. Many of these volunteer grief counselors are willing to offer assistance to bereaved individuals even if they are not in their local geographical area. The Program has also added to the website social media options such as Facebook, blogs, webinars, and online support groups as another way to augment community based grief support services.

- **Public Health Nurse Issues.**

Last year, *Kitty Roche and Gwen Edelstein* successfully administered a state wide survey to the SIDS Coordinators asking for responses to several questions. Those results indicated a desire to discuss the Disparities in SIDS Diagnoses statewide, and how this directly impacts SIDS Coordinators and services. The group as a whole desired a face to face meeting at least annually, and so one of the Annual Conference workshops will be for SIDS Coordinators. *Doctor Tom Keens* will give an update on the Disparities, and several Coordinators will present how this is being handled in their counties. Then there will be an opportunity for all to ask questions and share.



Gwen Edelstein

Kitty Roche

- **First Responder/Coroner Investigator Issues.**

These issues were addressed under "SIDS, Undetermined, or SUID Diagnoses" (see above).

- **Southern California Regional SIDS Council.**

Karen Jackson, P.H.N., President of the Southern California SIDS Council and Orange County SIDS Coordinator, reported on the activities of the *Southern California Regional SIDS Council*. The Council met on August 9th, and discussed final details for *Hearts United in Healing, 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. Council members also voted for the 2012 Boatwright Award recipient, who will be announced at the Conference on October 30th.



**Hannah Kinney.
M.D.**

The SIDS parent subcommittee has done a tremendous job in planning the pre-conference activities on their monthly Friday afternoon teleconferences. *Angela Amoroso, Drew Skinner, Jeri Wilson and Colleen Ma* have planned an evening of memorable events including a Meet and Mingle gathering for SIDS parents and family members, Service of Remembrance and Dessert Welcome Reception on Monday October 29th, at the DoubleTree Hotel Downtown Los Angeles. A Grandparent Workshop has been added in the afternoon, at the request of *Rachel Strickland*. She also offered to facilitate. She said it is invaluable as many grandparents attend the conference, but they often do not feel that the parent or professional workshops meet their needs. This feedback came from conference evaluations.



A room block has been arranged at the *Doubletree Hotel Downtown Los Angeles*. The hotel is within walking distance of the *California Endowment Center* (If you are a vigorous walker); otherwise, there will be shuttle service provided by the California SIDS Program.

- **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. They anticipate attending the upcoming conference in October, 2012. The SIDS Coordinators continue to receive support from their leaders to provide safe sleeping information. The Council is partnering with Nurse Family Partnership nurses to bring them up to speed in educating their clients.

- **State Report.**

Guey-Shiang Tsay presented a report of the California SIDS activities of the Maternal, Child, and Adolescent Health Section of the California Department of Public Health.

The State budget was signed by the Governor for FY 2012-13.

Doctor. Connie Mitchell, Branch Chief, MCAH Policy Development, accepted a new position, which is part of the New “Office of Health Equity”, to oversee the new unit to promote health for all Californians. The MCAH Division is in the process of filling her position. *Doctor Mitchell* sent the following message to the California SIDS Advisory Council:

Dear SIDS Advisory Council,

I just wanted to take a moment to thank you for participation on the SIDS Advisory Council and to let you know that you contribute tremendous value to our work in California to reduce SIDS.

I have served as the Branch Chief for Health Policy in Maternal, Child and Adolescent Health, providing supervision for Guey Tsay, who is the MCAH SIDS Coordinator. She has served both you and me in an exemplary manner, and I was so fortunate to get to know her, and through her, this Council.

As Guey has no doubt informed you, I have taken a position in the new Office of Health Equity, whose statutory goal is to achieve the highest level of health and mental health for all people with special attention focused on those who have experienced socioeconomic disadvantage and historical injustice, including, but not limited to, vulnerable communities and culturally, linguistically and geographically isolated communities.

I am sorry to leave MCAH but proud of the accomplishments we all have made together.

Dr. Shabbir Ahmad is recruiting a public health medical officer to replace me, and Guey will let you know as soon as the position has been filled. In the meantime, Guey is working closely with Sandra Bahn, my very capable Assistant Branch Chief at MCAH.

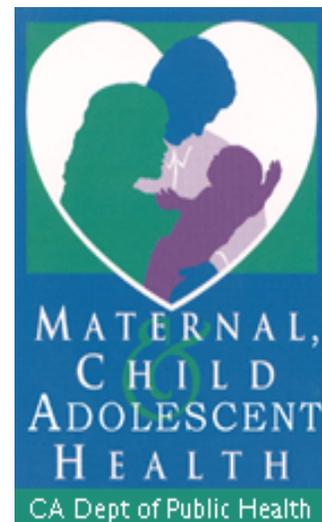
I send you my warm regards and gratitude for your commitment to the work of the Council.

Sincerely,
Connie Mitchell, M.D., M.P.H.

Doctor Mitchell has been a strong advocate for the SIDS program within the California Department of Public Health. We have benefitted from her leadership and commitment, and we will miss her. The Council wishes *Doctor Mitchell* the very best of luck, success, and fulfillment in her new position.

The Northern California SIDS Training in Richmond, California, on June 7, 2012, was very successful. We had 86 Public Health Professionals and 17 Emergency Personnel attending the training. Thanks to *Gwen Edelstein*, *Cheryl McBride* and to all of the guests including the speakers and SIDS parents participating in this SIDS training.

The next California SIDS Advisory Council face-to-face meeting will be held in Los Angeles from 1:00-4:00 P.M., on October 29, 2012. The meeting will start at 1:00 PM, so that the



Council members from Northern California will have enough time to travel in order to attend the meeting.

- **California SIDS Program Report.**

Gwen Edelstein submitted a detailed written report of California SIDS Program activities for April 1-June 30, 2012, that was distributed to all Council members and will be posted on the Program's website.

Gwen acknowledged *Dawn Dailey* and *Kitty Roche* for their support in welcoming newly appointed SIDS Coordinators. *The SIDS Handbook for Public Health Professionals* continues to be a helpful resource for newly appointed SIDS Coordinators; a packet of handbook updates was mailed to all SIDS Coordinators in June 2012, which included the revised AAP risk reduction/safe sleep recommendations and published 2011 AAP Policy Statement and Technical Report.

Gwen reported on the 2012 Annual SIDS Conference and pre-conference events, and stated a Save the Date announcement had recently been emailed to the Contractor's email data base. Complete details for these events will be posted on the Program's website within the next few days; the conference registration form and flyer have already been posted on the website calendar for October 29-30, 2012. Council members were reminded to submit their conference registration forms and payment of fees. Receipts of payment will be issued by the California SIDS Program for submission to CDPH MCAH for travel reimbursement. Council members were encouraged to make their hotel reservations early as there is a limited room block at the DoubleTree by Hilton Los Angeles Downtown (formerly the Kyoto Hotel and Gardens).

Cheryl McBride stated there were 179 presumptive SIDS cases reported to the California SIDS Program for 2011 and 81 presumptive SIDS cases reported for 2012 through July 16, 2012. Compliance for 2011 for submission of both Coroner Notification Cards and for Public Health Services Reports forms is 97%. Compliance for 2012 for submission of Coroner Notification Cards through July 16, 2012, is 93% and for Public Health Services Report forms it is 59%. Compliance letters will be mailed to counties delinquent with submission of the State Coroner Notification Cards and Public Health Services Report forms in September 2012. The 2nd quarter Compliance Monitoring Report and June reports for Calendar Years 2011 and 2012 were disseminated to the Council and will be posted on the California SIDS Program website in the near future.



- **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.

- **Council Meetings in 2012.**

The *California SIDS Advisory Council* 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 remaining meeting for 2012 will be:

- 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.

Right before the *California SIDS Advisory Council* meeting on Monday, October 29, 2012, at the *California Endowment Center*, our Council Chair, *Tom Keens*, will hold his traditional and highly ceremonial walk to *Cielito Lindo* on Olvera Street (the site of *El Pueblo de Nuestra Señora de los Angeles de Porciúncula*, where Los Angeles was founded on September 4, 1781), to buy and eat arguably the World's Greatest Taquitos. Meet at the California Endowment Center at 12:30 p.m. We will walk to *Cielito Lindo*, and you may eat your taquitos during the Council meeting.

- **Adjournment.**

The meeting was adjourned at 3:15 P.M.

Respectfully submitted,

Kathleen Beichley
Secretary, California SIDS Advisory Council

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

Gwen Edelstein, R.N., P.N.P., M.P.A.
Program Director, California SIDS Program



Diagnosing the Cause of Death for Infants Dying Suddenly and Unexpectedly

Diagnosing the cause of death for infants who die suddenly and unexpectedly has become increasingly difficult. In California, and in much of the rest of the world, there is a disparity in the way the causes of death for these infants are determined. In some jurisdictions, such infants may have a cause of death listed as "SIDS", in some "Undetermined", in still others "Sudden Unexplained Infant Death". This has resulted in confusion in the California SIDS community. Are coroners trying to suggest that babies in these diagnostic groups are fundamentally different? Should parents of a baby who died from "SIDS" be more reassured than a parent whose baby was listed as "undetermined"? Should parents be treated differently, or offered different resources, depending on the diagnosis used?

The *California Sudden Infant Death Syndrome Advisory Council* has spent considerable time and effort investigating these issues, and it has come to consensus for the State of California. The *Council* has determined the following:

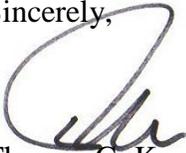
- Coroners and medical examiners in California face considerable challenges in determining the cause and manner of death for infants who died suddenly and unexpectedly. These deaths were not witnessed, so Coroners must attempt to reconstruct the possible cause of death by investigating circumstantial evidence from the death scene and autopsy. Most deaths are associated with one or more potential risks or potentially unsafe sleeping environments, which complicate interpretation of the cause of death. While coroners are doing their best to accurately determine the cause of death, certainty is rarely possible. Thus, some disparity in how these babies are diagnosed is inevitable. It is not likely, or perhaps even desirable, that complete consensus is achieved by all California coroners to diagnose these babies the same.
- Coroners may have differing philosophies and/or practices which will influence them to make certain diagnoses more commonly than others. However, in the absence of a clear-cut finding indicating a specific cause of death, it is clear that the terms "SIDS", "undetermined", "sudden unexpected death of infancy", and "sudden unexpected infant death", are being used interchangeably. To coroners, these all mean that the death was sudden and unexpected, and that it was unexplained (that is, we do not know the cause). Therefore, the California SIDS community, public health departments, and everyone interacting with these families should view these diagnoses as being equivalent and meaning the same thing.
- Coroners in keeping with the SIDS legislative mandates (California Government Code 27491.41) should refer all sudden unexpected infant deaths to their local health jurisdiction's SIDS Program Coordinator within 24-hours of completing the autopsy. This trained Public Health Nurse/Social Worker in accordance with California Health and Safety Code 123740 should make contact with the family within three working days to provide counseling, support and bereavement assistance. This should include families where the baby is diagnosed as dying from "SIDS", as well as families with diagnoses such as "undetermined", "sudden unexpected death in infancy", "sudden unexpected infant death", etc.
- Contact by the local health jurisdiction should be a face-to-face visit, a group visit or a telephone call. However, a home visit is recommended whenever possible. Those who

experience a sudden unexpected infant death, regardless of the diagnosed cause, should not be treated differently. A home visit is the preferred supportive intervention as this provides an opportunity for the bereaved to express their feelings, gain an in depth understanding of the circumstances of their infant's death, and ask questions. For many, the home visit is the foundation of their support.

The Council is aware that for some parents, receiving a diagnosis of "undetermined" has been interpreted as somehow tainting the death as suspicious, compared to a diagnosis of "SIDS". It is clear from discussions with coroners and medical examiners that this is not their intent. Rather, in the minds of California coroners and medical examiners, these diagnoses are essentially interchangeable, and they imply only that the death was sudden and unexpected on the one hand, and unexplained on the other. It is now the responsibility of public health departments, coroners, and SIDS experts not to perpetuate the above view, but to emphasize that these deaths are similar in the eyes of those making the diagnoses, and that parents of all of these babies are entitled to the same support, education, empathy, and respect.

The *California Sudden Infant Death Syndrome Advisory Council* officially and unanimously approved this recommendation at its meeting on August 14, 2012.

Sincerely,



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

California SIDS Advisory Council



Kathleen Beichley



Dawn Dailey



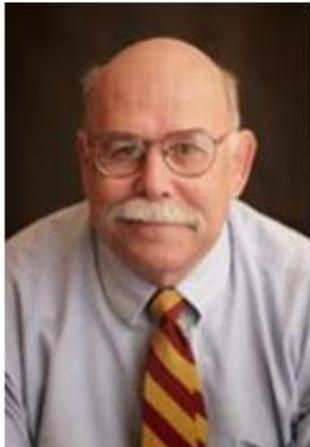
Yolanda DeMello



Steve Durfor



Lorie Gehrke



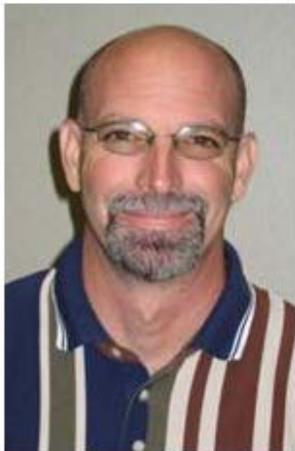
Tom Keens



James Ribe



Kitty Roche



Dennis Watt



Karen Jackson



Aline Armstrong

