



# California Sudden Infant Death Syndrome Advisory Council

## Minutes of the January 22, 2013, Meeting

### Members of the Council

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

**Lorie Gehrke,** *Vice Chair,*  
*SIDS Parent.*

**Kitty Roche, R.N., P.H.N.,**  
**B.S.N., M.S.W.** *Secretary,*  
*Public Health Nurse*

**Kathleen Beichley,** *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.*

**Dennis H. Watt,** *Coroner.*

**Penny F. Stastny, R.N.,**  
**B.S.N., 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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### California SIDS Advisory Council Los Angeles, California, October 29, 2012

- **Members Present:** Thomas G. Keens, M.D., *Chair*; Kitty Roche, *Secretary*; Aline Armstrong, P.H.N.; Kathleen Beichley; James K. Ribe, M.D.; Penny F. Stastny, R.N., B.S.N., and Dennis Watt, Coroner.
- **Members Absent:** Dawn Dailey, RN, PHN, PhD; Yolanda DeMello, M.S.P.M; Steve Durfor; and Lorie Gehrke, *Vice Chair*.
- **State and California SIDS Program:** Gwen Edelstein, RN, PNP, MPA; Carrie Florez; Cheryl McBride, RN; and Guey-Shiang Tsay, RN, MSN.
- **Guests:** Luz Arboleda-Babcock, P.H.N.; Lidia Escobar, L.C.S.W.; Catherine Farnham, P.H.N.; Karen Jackson, R.N.; Colleen Ma, C.L.E.; Connie Sanchez; Jessica B. Spearman; and Steve Wirtz.
- The meeting was held by telephone conference call. The meeting was called to order at 1:30 P.M., on January 22, 2013.
- **Introductions.**  
Council members, state staff, and guests introduced themselves.

- **Council Membership.**

The Council congratulated *Penny F. Stastny*, newly elected President of the Southern California Regional SIDS Council for 2013-2014, and welcomed her as an *ex officio* member of the Council. The Council also congratulated *Aline Armstrong* on her re-election as President of the Northern California Regional SIDS Council, and welcomed her return as an *ex officio* member of the Council.



Penny Stastny and Aline Armstrong

- **SIDS Risk Reduction Education.**

**New NIH Guidelines on *Safe Infant Sleep*.**

At our October 29, 2012, Council meeting, *Gwen Edelstein* distributed the website announcement of October 8, 2012, by the National Institute of Child Health and Human Development (NICHD), which outlined details of the agency's newly launched *Safe to Sleep* Campaign. (To access go to: <http://www.nichd.nih.gov/SIDS> ). *Gwen* provided the Council with copies of the new brochure *Safe Sleep for Your Baby: Reduce the Risk of SIDS and Other Sleep-Related Causes of Infant Death* and the handout, *What Does a Safe Sleep Environment Look Like?* These materials incorporate the 2011 American Academy of Pediatrics (AAP) Safe Sleep Recommendations and the new Safe to Sleep logo.

*Gwen Edelstein* briefly reviewed some of the key discussion points raised at the October 29, 2012, meeting about the brochure. She noted it includes a reference to Sudden Unexpected Infant Death (SUID) and states that "Many unexpected infant deaths are accidents, but a disease or something done on purpose can also cause a baby to die suddenly and unexpectedly."; the content is very high literacy ; there are statistical data that may not have much meaning for the general public; there is no mention that the safe sleep measures are evidenced-based and reflect the latest recommendations of the AAP; returning the baby back to their sleep area after breastfeeding is included rather than reinforcing that a baby should *always* be returned to its own sleep area; light sleep wear is recommended although AAP suggests use of a one piece sleeper and



no head covering but these messages are not included. *Gwen Edelstein* also commented that the handout *What Does a Safe Sleep Environment Look Like?* has been added to the California SIDS Program website upon approval from CDPH MCAH. This handout is lower literacy, the graphics clearly depict a safe sleep area, and the key messages are easy to understand. The video, *Safe Sleep for your Baby* is very well done, is culturally competent and takes place in a park with several parents talking casually about ways to keep sleeping baby safe.

The *California SIDS Advisory Council* has a legislative mandate to advise the *California Department of Public Health* on SIDS issues. Therefore, the Council discussed these materials.

Council members thought that the video, *Safe Sleep for Your Baby*, was outstanding, and highly recommended to the California Department of Public Health that it be used in SIDS Risk Reduction and Infant Safe Sleep education.



The Council was concerned that the *Safe Sleep for Your Baby* brochure was at a high literacy level. However, the Council agreed that the information was accurate, and recommended that the brochure and English/Spanish *What Does a Safe Sleep Environment Look Like?* handout also be used in SIDS Risk Reduction and Infant Safe Sleep education.

Although there was some discussion about the California SIDS Program making its own Safe Infant Sleep brochure, there is not currently sufficient funding to do so. However, some Counties or other agencies within California may wish to do so. *Gwen Edelstein* noted that NICHD has printed brochures targeting the general population, African Americans, Native Americans and Spanish speaking families. These can be ordered in quantities and are free. A brochure is currently being developed in English/Spanish for grandparents along with Safe Sleep doorknob hangers in English, Spanish, and for African American/Native American populations. The *Safe Sleep for Your Baby* DVD can be ordered in quantities of five and duplicated since it is public domain. It will be available in Spanish at a later date.

### **Los Angeles County Infant Safe Sleep Campaign.**

The *Los Angeles County Infant Safe Sleeping Campaign* has spent the final quarter of the *Safe Sleep for Baby* campaign conducting community forums and “train the trainer” presentations, and creating additional training materials for the professionals and caregivers.

In preparation for year-two of the grant and the full campaign and media push roll out in early 2013, the *Los Angeles County Infant Safe Sleeping Campaign* selected a new campaign name, tagline and logo. “Safe Sleep for Baby” was chosen as the official campaign name with the accompanying tagline, “Don’t Wake Up to a Tragedy.” The new campaign name, tagline and logo will be incorporated into all existing materials and be used on all new material in the coming months.

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 and campaign for when the campaign and media push roll out in 2013. As of January, 1, 2013, the campaign has completed a total of 30 community forums. Presentations were conducted at parenting classes, resource fairs, after school parent meetings, and more. A PowerPoint describing unsafe and safe sleeping is used to both describe and depict what is unsafe, what can happen and the safest way to put a baby to sleep. Presentations are conducted in both English (by Project Manager *Jessica Spearman*) and in Spanish (by Project Assistant *Connie Sanchez*).



**Jessica B. Spearman**

After receiving an abundance of community forum presentation requests, the *Los Angeles County Infant Safe Sleeping Campaign* realized the need to shift from community forum presentations that focused on informing parents and caregivers about infant safe sleeping, to conducting “train the trainer” presentations. By training agencies, community based organizations, and providers about infant safe sleeping, this would allow a broader number of parents and caregivers to receive infant safe sleeping information and create sustainability for the campaign. Additionally, by training providers and professionals the campaign will succeed in creating familiarity with the issue for when the campaign and media push roll out in 2013. As of January 1, 2013 the *Los Angeles County Infant Safe Sleeping Campaign* has conducted 22 “train the trainer” presentations.

Audiences spoken to include various Department of Children and Family Services offices throughout the county, community partnership meetings, faith based council meetings, medical professionals, and more.

To accompany the “train the trainer” presentations, the *Los Angeles County Infant Safe Sleeping Campaign* created a Training Tool Kit. The tool kit includes information that will help a provider educate both their peers and clients about infant safe sleeping. Items in the tool kit include: A copy of the *Denise Bertone* and *Dr. Carol Berkowitz* training video, "A



Space of My Own: Reducing Infant Sleep-Related Infant Deaths in LA County," highlighting infant safe sleeping and abusive head trauma; Copies of the Safe Sleep for Baby PowerPoint Presentation (in English and Spanish); Quizzes (in English and Spanish); Safe sleep training points and facts sheet (in English and Spanish); A frequently asked questions and answers sheet; and more. Tool kits are handed out at all "train the trainer" presentations. Materials were completed in December, 2012, and they were immediacy placed on the ICAN Safe Sleep website, [www.ican4kids.org/safesleep](http://www.ican4kids.org/safesleep). In December of 2012, ICAN Associates and social marketing agency *Rogers Finn Partners* worked together to redesign the ICAN Safe Sleep website to reflect the campaign's color scheme and branding. The complete training kit is available for download on the newly redesigned site.

To further address sustainability and training providers and professionals, the *Los Angeles County Infant Safe Sleeping Campaign* has begun to create an online e-Learning. The half hour e-Learning will be placed on SABA, the LA County training system and will be made available to all county agencies. The course will educate professionals about infant safe sleeping highlighting what is unsafe, the various ways babies can die, and the safest way to put a baby to sleep. Once complete, *Los Angeles County Infant Safe Sleeping Campaign* will make it accessible to professionals outside of county workers.

To accompany the e-learning the *Los Angeles County Infant Safe Sleeping Campaign* and Los Angeles County Infant Safe Sleeping Task Force have begun to create a 30 second Public Service Announcement. The PSA will be created as informational tool for parents and caregivers. Both the e-Learning and PSA are expected to be completed by the first quarter of 2013.

During the fall of 2012, and winter of 2013, the *Los Angeles County Infant Safe Sleeping Campaign* conducted an informal pilot program or "Soft Launch" in Compton, California. The goal of the soft launch was to saturate an area, Compton, with safe sleep information, presentations, and training tool kits. The soft launch has served as a test run for materials, tactical outreach, and collaboration with stakeholder agencies. All information gathered (including response to materials, outreach suggestions, etc.) will influence the design of year-two and the full campaign roll out.



ICAN Associates will spend the beginning of 2013 wrapping up year one of the campaign and preparing for year two. Immediate tasks for year two include completing the e-learning course, completing the 30 second PSA, creating a partnership memo for the 32 partnerships ICAN will establish with stakeholder agencies throughout year two, and creating an official campaign

website in English and Spanish. Additionally, ICAN Associates will meet with *Rogers Finn Partners* and *First 5 LA* to finalize the strategic communications plan for year-two including finalizing campaign materials, tactical outreach, and strategy.

The California SIDS Advisory Council was extremely impressed with the work already completed by the *Los Angeles County Infant Safe Sleeping Campaign*, and the Council expressed its appreciation for all the *Los Angeles County Infant Safe Sleeping Campaign* has achieved.

### **Preventing Unsafe Infant Sleep Workgroup**

*Steve Wirtz*, Ph.D., Chief, Violent Injury Surveillance Unit, Safe and Active Communities (SAC) Branch of CDPH, provided an update. At the SAC Branch, our Kids Plates Program funds, that had been directed to local agencies to promote safe sleep prevention, are no longer available. The Bureau of State Audits conducted an audit that found problems with the way the program had been structured and administered. Remaining local assistance funds have been reallocated through three competitive regional grants. Unfortunately as a result, there are no current Kids Plates funds directed to safe sleep activities. As reported in the past, we had also lost our CDC funds for core injury prevention activities under which we were able to allocate some staff time to safe sleep work. So we have been limited in what we can do to support the SIDS Council efforts. We will continue to provide technical assistance on safe sleep surveillance and prevention efforts (e.g., Child Care Licensing Safe Sleep Workgroup).



Steve Wirtz, Ph.D.

We want to applaud efforts of California SIDS Advisory Council for your sensitive and thoughtful resolution on "Diagnosing the Cause of Death for Infants Dying Suddenly and Unexpectedly". From a public health perspective, we believe this will help make prevention messages more consistent and effective, given the current diagnosis and classification limitations.

*Gwen Edelstein* reported that a review of child care health and safety regulations in California was conducted as part of a Department of Defense Military Child Care Initiative administered by Child Care Aware® of America. A statewide Health and Safety Regulatory Workgroup was convened as a stakeholder group to: 1) support best practices and improve child care health and safety standards in California; and 2) make recommendations to the California Department of Social Services (CDSS) Community Care Licensing Division (CCLD) on regulatory reform for California's child care health and safety regulations. Safe sleep practices was identified as one the areas needing to be addressed. A Safe Sleep Subgroup was then formed to gather and present the group's findings and recommendations to the California Department of Social Services Community Care Licensing Division (CDSS CCLD) in the form of a white paper.



Gwen Edelstein

Under the leadership of *Mary Beth Phillips, Ph.D.*, California Military Child Care Liaison, the Safe Sleep Subgroup was convened and collaborated on a regular basis for the past several months to develop a white paper. *Lucy Chaidez* from the Emergency Medical Services Agency (EMSA) and *Nathan Salomonis*, a Bay area SIDS father, have been instrumental in moving this forward. *Carrie Florez*, *Steve Wirtz* and *Gwen Edelstein* have served as “consultants” by providing evidence based SIDS risk reduction/safe sleep research as identified by the AAP in their 2011 technical report; statistical data and resources for safe sleep education and outreach in child care setting.

The Health and Safety Regulatory Workgroup met on December 4, 2012, at the EMSA office in Rancho Cordova. CDSS Child Care Licensing presented a brief update and noted their agency has received the white paper and is moving forward with a strategic plan. As needed CDSS CCL will call upon the workgroup to provide additional information and respond to questions as they arise. *Nathan Salomonis* is continuing to provide support by looking at what other states have done in regards to implementing safe sleep regulations in licensed child care facilities.

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

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

In California, there has been inconsistency 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. The *SIDS Summit* was summarized in the October 27, 2011, Minutes of the California SIDS Advisory Council. For details, please access the California SIDS Program website for the Minutes of the October 27, 2011, <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 making these diagnoses, the diagnoses of SIDS, SUID, and undetermined are intended to refer to the same thing. That is, that the death is unexpected on the one hand, and unexplained on the other. Therefore, it is now 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.

A document to explain the shift in diagnosis whereby SIDS, SUID and undetermined are used interchangeably, was approved by the *California SIDS Advisory Council* at its August 14, 2012, meeting as an official recommendation to the California Department of Public Health (copy appended to these Minutes). This recommendation was forwarded to the Department. On December 17, 2012, the *California Department of Public Health* sent a letter to all California County Coroners, Sheriff Coroners, Medical Examiners, SIDS Coordinators, and Maternal Child and Adolescent Health Directors emphasizing the following points (copy appended to these Minutes):

- With respect to providing education and grief support services to families who have experienced a sudden and unexpected infant death, the following diagnoses are equivalent and support services should be provided to all: SIDS, Crib Death, Sudden death in infancy (SDII), Sudden unexplained death in infancy (SUDI), Sudden unexplained death (SUD), Sudden unexplained infant death (SUID), Sudden infant death (SID), and Undetermined.
- Coroners and Medical Examiners should voluntarily refer all sudden and unexpected infant deaths to the local Maternal Child and Adolescent Health Program.
- Any person interacting with families who may receive any of the above diagnoses should be provided with the same grief and bereavement support and SIDS education as a family who receives a SIDS diagnosis.
- Local Maternal Child and Adolescent Health Programs should provide grief and bereavement support and SIDS education to all parents/caregivers who experience a presumed SIDS death (including all above diagnoses).
- It is difficult for parents of the infant to deal with such a tragic loss, and the availability of support services to help them work through their loss could be critical and beneficial.

It is now important for the California SIDS Advisory Council, members of the Southern and Northern California Regional SIDS Councils, County SIDS Coordinators, and leaders in the California SIDS Community to educate parents and caregivers that in California, the diagnoses of SIDS, SUID, SUDI, Undetermined, etc. are equivalent in the minds of those making these diagnoses. They all mean that an infant death was sudden, unexpected, unobserved, and unexplained after a thorough investigation. *Previously*, these diagnoses may have been used differently. However, *currently* we should not perpetuate the myth that one diagnosis is somehow better than another. *Doctor Keens* challenged those on the teleconference to take a lead in this education for the ultimate benefit of parents of these babies. To perpetuate a belief that some diagnoses imply more guilt than others will cause some parents needless guilt and may worsen their grief. *Doctor Keens* volunteered to write a lay explanation that can be used by SIDS coordinators, SIDS support groups, etc. to explain this.

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

At the October 29, 2012, Council meeting, there was discussion suggesting that SIDS parents are being treated like criminals by first responders. The Council was reminded that education is currently mandated for first responders in California. No one on the teleconference had any information about whether this remained an issue. The Presidents of the Southern and Northern California Regional SIDS Councils were asked to query their members to see if problems

experienced by SIDS parents by first responders are re-emerging as problems. They will report back at the next Council meeting.

- **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 was specifically designed for SIDS Coordinators. *Kitty Roche* was the workshop moderator and introduced the session. *Doctor Tom Keens* gave an update on the Disparities, and three Southern California SIDS Coordinators, *Angel Hopson* (LA), *Deja Castro* (Riverside) and *Danielle Sees* (City of Long Beach), presented an overview on how they are case managing sudden infant deaths with the change in diagnosis. *Kitty* provided input about the grief and bereavement support services offered in San Diego County. Then there was an opportunity for SIDS Coordinators from other local health jurisdictions to ask questions and share.

*Gwen Edelstein* shared that *Deja Castro* took notes of the session and a summary of the proceedings was developed and has been posted on the California SIDS Program website along with *Doctor Keens'* power point slides and handouts. (To access the summary go to <http://www.californiasids.com/Universal/MainPage.cfm?p=4481>)

In reviewing the conference evaluations from this session, the workshop was rated 4.91 out of a possible 5 (excellent). There were a total of 21 Local Health Jurisdictions represented in this workshop. SIDS Coordinators commented that the workshop provided helpful ideas on how to work with their local coroner and practical approaches to supporting bereaved families. Several remarked they enjoyed the opportunity to network and share resources.

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

*Dennis Watt* reported that the California State Coroners' Association is considering holding a repeat of their SIDS Summit, which was originally held in 2011. There are no specific plans as yet, but they will be considering this over the next year.

- **Southern California Regional SIDS Council.**

The newly elected President of the Southern California Regional SIDS Council is *Penny F. Stastny, R.N., B.S.N.*, the retired SIDS Coordinator for the Orange County Health Care Agency, and public health nurse in the Los Angeles County Department of Public Health. The Vice President is *Jeri Wilson, M.S.W.*, a SIDS parent in San Diego County. The Secretary is *Colleen Ma*, a SIDS Parent and President of the Guild for Infant Survival, Orange County.

*Penny F. Stastny, R.N., B.S.N.*, President of the Southern California SIDS Council, reported on the activities of the *Southern California Regional SIDS Council*. She started by acknowledging that she was pleased and honored to represent the *Southern California Regional SIDS Council* as the new incoming President serving for the next two year term 2013-2014. *Penny Stastny* was one of the original nine appointed members to the *California SIDS Advisory Council* in 1990 by DHS. *Penny Stastny* and *Linda Levisen* were chosen to represent Public Health

Nursing. *Penny* resigned in 1999, when she left the Orange County SIDS Coordinator position (which she resumed one year later).

Last *Southern California Regional SIDS Council* meeting was held November 8, 2012. In attendance were five SIDS parents; five PHNs- SIDS Coordinators representing Los Angeles, San Diego, Riverside, and Orange Counties; *Dr. Tom Keens* from CHLA /USC; and *Dr. Jim Ribe* representing LA County Coroner's office. The California SIDS Program was represented by its director, *Gwen Edelstein*. The next four meetings in 2013, will be on February 7, 2013; May 9, 2013; August 8, 2013; and November 14, 2013.



Southern California Regional SIDS Council.  
November 8, 2012.

A good portion of our November 8, 2013, meeting was spent discussing the success of our 32<sup>nd</sup> *Annual SIDS Conference, "Hearts United in Healing"*, held at the California Endowment Center in downtown Los Angeles on October 30, 2012. Overall the conference received an overwhelmingly great response. *Gwen Edelstein* can give more input from the evaluations in her report. The Council thanked *Gwen Edelstein*, *Cheryl McBride*, and *Karen Jackson* for the phenomenal job they did to orchestrate the Conference. We received very positive feedback on our keynote speaker, internationally renowned researcher, *Dr. Hannah Kinney* from Harvard University, who spoke on her most SIDS research of the past few decades. Although she was unable to fly out for the conference, thanks to advancement in technologies we were able to see and hear her via internet/satellite connections. *Doctor Kinney* was also able to be interactive with the audience and answer questions, which was very well received. The SIDS parent subcommittee, including *Jeri Wilson*, *Colleen Ma*, *Angela Amoroso*, and *Drew Skinner* did a tremendous job in planning the pre-conference activities, including the "Service of Remembrance and a Dessert Welcome Reception on Monday, October 29, 2012.



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Jeri Wilson

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*The Southern California Regional SIDS Council* congratulated its member, *Jeri Wilson*, as the winner of the 2012 Daniel E. Boatwright Award "for extraordinary public service on behalf of Californians touched by SIDS".

The *Guild for Infant Survival, Orange County* held a luncheon on October 17, 2012, to honor Professors *Henry Krous and Tom Keens* for their services to Southern California improving SIDS services, education, and research.



Henry Krous, Penny Stastny, and Tom Keens. OCGIS Luncheon. October 17, 2012.

At Children’s Hospital Los Angeles (CHLA; and, of course, USC), 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. Two of the CHLA nurses on 5-East, *Myrel Catbagan and Leslie Greene*, has also been working to improve safe infant sleep on her ward at CHLA. They will be joining this larger project, as their enthusiasm will be helpful, especially to enlist to support of nurses in the hospital. *Penny Stastny* is serving as a consultant, and *Tom Keens* is supervising the interns’ project. The project will begin by evaluating staff knowledge and practices perform crib audits. This will be followed by educational interventions, and then an assessment of the program’s impact. These investigators believe that this project will help to develop guidelines for safe infant sleep in Children’s Hospitals, which care for children with chronic and severe illnesses, which is much different than existing guidelines for normal newborn nurseries.



Sandra Gildersleeve, M.D. Manu Raam, M.D. Myrel Catbagan, R.N. Leslie Greene, R.N.

• **Northern California Regional SIDS Council.**

*Aline Armstrong, P.H.N.*, was re-elected President of the Northern California Regional SIDS Council. She is the SIDS Coordinator for San Francisco County. The Vice President is *Lorie Gehrke*, a SIDS parent and President of the SIDS Alliance of Northern California. The Secretary is *Michelle Scott, P.H.N.*, the SIDS Coordinator for San Joaquin County.

The Northern California Regional SIDS Council will select a representative to present SIDS updates at the MCAH Action meetings. The MCAH Action meeting is May 22, 2013. The next

five meetings of the Council in 2013, will be on February 1, 2013; March 15, 2013; May 17, 2013; July 19, 2013; and November 15, 2013.

The Northern California Regional SIDS Council is informing everyone to save the dates of October 3-4, 2013, for the 33<sup>rd</sup> Annual California SIDS Program Fall Conference, which will be held at the California Department of Public Health in Sacramento, California.



Northern California Regional SIDS Council, February 1, 2013.

- **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.

- We have distributed the letter signed by the MCAH Division Chief to Local MCAH Directors, SIDS Coordinators and County Coroner's office regarding sudden unexpected infant death referrals from Coroners/medical examiners and providing support services to parents/caregivers who experience a presumed SIDS death from local health jurisdictions. The letter has been posted at the SIDS program website. Thank you to the *California SIDS Advisory Council* for their recommendation, and thank you to *Steve Durfor* for his assistance in the distribution of the letter to Coroner and Medical Examiner Office in California. A copy of the letter is appended to the end of these Minutes.
- Thank you to *Southern California Regional SIDS Council* and *Karen Jackson*, and the *California SIDS Program*, *Gwen Edelstein* and *Cheryl McBride*, for putting on the highly successful 32<sup>nd</sup> Annual California SIDS Conference on October 29-30, 2012, in Los Angeles.
- The Northern California SIDS Training for Emergency Personnel and Public Health Professionals will be held on January 24, 2013, at the CDPH complex in Sacramento. Thank you to *Gwen Edelstein* and *Cheryl McBride* for preparing and coordinating the training. There are about 160 people registered for the training.
- MCAH is currently in the process of developing plan for the 2015 – 2019 Title V Needs Assessment



- **California SIDS Program Report.**

*Gwen Edelstein* submitted a detailed written report of California SIDS Program activities for October 1 to December 31, 2012, that was distributed to all Council members and will be posted on the Program's website.

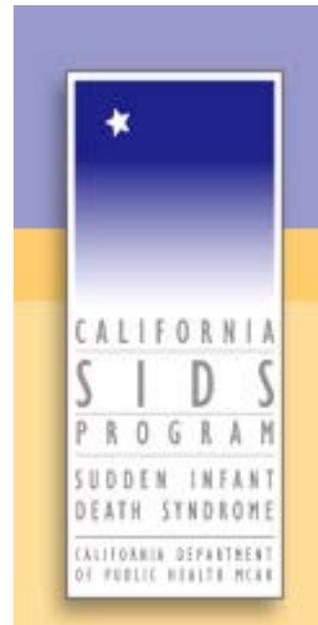
*Gwen* reported there were 105 attendees for the Annual SIDS Conference held on October 30, 2012, in Los Angeles; three others exhibited but did not attend the conference. There were 33 SIDS/SUID parents/family members and 36 PHNs/SIDS Coordinators in attendance. Only 69 evaluations were received representing 66% of the attendees. The overall conference was rated as 4.86 out of 5 (very good/excellent). The most useful general sessions were the research update by *Dr. Kinney* and the SIDS parent panel. There was good feedback on the afternoon workshops. The least useful session was the closing general session with the drumming; some commented they enjoyed the activity but were not sure of the connection with the rest of the conference. *Gwen Edelstein* also recognized the dedication of *Angela Amoroso, Drew Skinner, Colleen Ma, and Jeri Wilson*, SIDS parents from the Southern California Regional SIDS Council, who worked diligently to plan the pre-conference Meet and Mingle, Celebration of Love and Dessert Welcome Reception.

During this report period, *Gwen Edelstein* shared that there were newly appointed SIDS Coordinators for Los Angeles, Siskiyou, Madera, San Bernardino and Yolo counties. The California SIDS Program continues to provide new coordinators with the *SIDS Handbook for Public Health Professionals* and either *Kitty Roche* or *Dawn Dailey*, the PHN California SIDS Advisory Council representatives, provides a welcome orientation. The Northern California SIDS Training for Emergency Personnel and Public Health Professionals is scheduled for Thursday, January 24, 2013, at the CDPH facility in Sacramento. There are currently over 160 registrants with 31 local health jurisdictions represented. The Southern California training will take place on April 18<sup>th</sup> in Bakersfield. (Kern County).

*Cheryl McBride* presented the October-December, 2012, Compliance Monitoring Report and Presumed SIDS Cases' Report for 2011 and 2012 by County of Residence which were distributed to members and will also be posted on the Program's website. She reported there have been 181 presumptive SIDS cases reported to the California SIDS Program for 2011. For 2012 there have been 163 presumptive SIDS cases reported through January 11, 2013. Compliance for submission of Coroner Notification Cards (CNCs) is 94% and for Public Health Services Report (PHSR) forms compliance is 87%. Quarterly compliance letters were mailed on December 21, 2012, to seven County Coroner Offices and five SIDS County Coordinators delinquent with submitting State Coroner Notification Cards and Public Health Services Report forms.

- **Doctor James Ribe Honored.**

*Doctor James Ribe* reported that he has have been appointed to a countywide committee to report to the Los Angeles County Board of Supervisors concerning unifying the County's data on child safety/child protection pursuant to the mandate of AB 636.



James Ribe, M.D.

• **Council Meetings in 2013.**

The remaining *California SIDS Advisory Council* meetings for 2013 are:

- Meeting by telephone conference call, Tuesday, April 30, 2013, 1:30-3:30 P.M.
- Meeting by telephone conference call, Tuesday, August 13, 2013, 1:30-3:30 P.M.
- In-person Meeting: Thursday, October 3, 2013, 1:00-4:00 P.M., the day before the 33<sup>rd</sup> *Annual California SIDS Conference* in Sacramento, 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.

• **Adjournment.**

The meeting was adjourned at 3:23 P.M.

Respectfully submitted,

Kitty Roche, R.N., P.H.N., B.S.N., M.S.W.  
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



Kathleen Beichley



Dawn Dailey



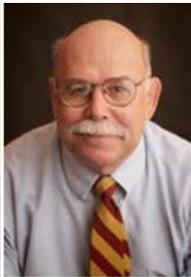
Yolanda DeMello



Steve Durfor



Lorie Gehrke



Tom Keens



James Ribe



Kitty Roche



Dennis Watt



Penny Stastny



Aline Armstrong

## 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:

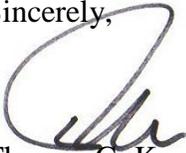
- Coroners and medical examiners in California face considerable challenges in determining the cause and manner of death for infants who died suddenly and unexpectedly. These deaths were not witnessed, so Coroners must attempt to reconstruct the possible cause of death by investigating circumstantial 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.

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RON CHAPMAN, MD, MPH  
Director & State Health Officer

State of California—Health and Human Services Agency  
California Department of Public Health



EDMUND G. BROWN JR.  
Governor

DATE: DECEMBER 17, 2012

TO: COUNTY CORONERS, SHERIFF CORONERS AND MEDICAL EXAMINERS  
SUDDEN INFANT DEATH SYNDROME (SIDS) COORDINATORS  
MATERNAL, CHILD AND ADOLESCENT HEALTH (MCAH) DIRECTORS

SUBJECT: SUDDEN, UNEXPECTED INFANT DEATH TIMELY REFERRALS AND PROVIDING  
GRIEF/BEREAVEMENT SUPPORT SERVICE TO PARENTS/CAREGIVERS WHO  
EXPERIENCE A SUDDEN, UNEXPECTED INFANT DEATH

This letter is in reference to the current MCAH Scope of Work (SOW). Within the SOW, each Local Health Jurisdiction (LHJ) MCAH program is required to contact all parents/caregivers who experience a presumed SIDS death to provide grief and bereavement support services. California HSC §123740, requires local health officers to contact persons having custody and control of the infant to provide information and support services. It is very critical that the LHJ receives the timely referral from the coroner/medical examiner's office in order for SIDS Coordinators/Public Health Professionals to provide grief/bereavement support services to all parents/caregivers who experience a presumed SIDS death.

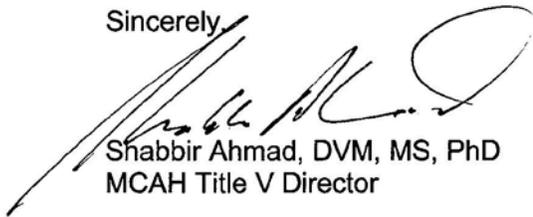
With the introduction of the International Classifications of Disease, 10<sup>th</sup> Revision (ICD-10) in 1999, causes of death listed on the death certificate that will be classified to SIDS (R95) in California include Crib Death, SDII (sudden death in infancy), SIDS, SUD (sudden unexplained death), SUID (sudden unexplained infant death), SUDI (sudden unexplained death, infant) and SID (sudden infant death). It is very important for the coroner/medical examiner's office to voluntarily refer all sudden and unexpected infant deaths to the local MCAH program, including deaths with an "undetermined" diagnosis. The California SIDS Advisory Council recommends that any person interacting with families who may receive one of these diagnoses be provided the same grief/bereavement support and SIDS education as a family who receives a SIDS diagnosis.

We are very grateful for the continued support of coroners/medical examiners referrals of sudden, unexpected infant deaths even with the continued suspension of the state mandates due to state budget constraints. We also appreciate local MCAH SIDS Coordinators/Public Health Professionals for providing grief/bereavement support services to all parents/caregivers who experience a presumed SIDS death that are referred to their offices. The collaboration between the coroner/medical examiner office and local MCAH Program is essential when an infant dies suddenly and unexpectedly. It is difficult for the parents of the infant to deal with such a tragic loss and the availability of support services to help them work through their loss could be critical and beneficial.

CORONERS-AND MEDICAL EXAMINERS  
SIDS COORDINATORS  
MCAH DIRECTORS  
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December 17, 2012

We look forward to continuing to work with all of you together. If you have questions, please feel free to contact Guey-Shiang Tsay, Nurse Consultant for the SIDS Program, at [Guey-Shiang.Tsay@CDPH.ca.gov](mailto:Guey-Shiang.Tsay@CDPH.ca.gov), or Carrie Florez, Research Scientist for Epidemiology Evaluation and Data Operations, at [Carrie.Florez@cdph.ca.gov](mailto:Carrie.Florez@cdph.ca.gov).

Sincerely,



Shabbir Ahmad, DVM, MS, PhD  
MCAH Title V Director