



# California Sudden Infant Death Syndrome Advisory Council

## Minutes of the November 18, 2015, Meeting

Embassy Suites Hotel  
800 North Central Avenue, Glendale, California

### 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*

Kris Concepcion, *First  
Responder.*

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

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

Rachel Strickland, *SIDS  
Parent.*

Dennis H. Watt, *Coroner.*

Penny F. Stastny, R.N.,  
B.S.N., P.H.N.,  
*President, Southern Calif.  
Regional SIDS Council.*

Susana Flores, P.H.N.,  
*President, Northern Calif.  
Regional SIDS Council.*

### Council Chairperson:

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Members of the California SIDS Advisory Council.  
November 18, 2015.

- **Members Present:** Thomas G. Keens, M.D., *Chair*; Lorie Gehrke, *Vice Chair*; Kitty Roche, R.N., P.H.N., B.S.N., M.S.W., *Secretary*; Kathleen Beichley; Kris Concepcion; Dawn Dailey, R.N., P.H.N., Ph.D.; Susana Flores, P.H.N.; James K. Ribe, M.D., J.D.; Rachel Strickland; Penny F. Stastny, R.N., B.S.N., P.H.N.; and Dennis H. Watt.
- **Members Absent:** None.
- **State and California SIDS Program:** Addie Aguirre; Kay Evans, R.N.; Carrie Florez; Susan Gonzalez; Deborah L. Hunt, Ph.D.; Mollie Mayer; Guey-Shiang Tsay, R.N., M.S.N.; Mari Taylan-Arcoleo, M.P.H.
- **Guests:** Aline Armstrong, *(by telephone)*; Kelley Barragan; Claudia Benton, M.S.N., R.N.-B.C., P.H.N.; Denise Bertone, R.N.; Robin Bunch, P.H.N., *(by telephone)*; Deja Castro, R.N., P.H.N.; Lucy Chaidez, *(by telephone)*; Terrie Davis; Sally Eberhard; Julie

Flanagan; Julie Espinosa Garcia, M.S.W., L.C.S.W.; Kitty Gay, R.N.; Michelle Herrera; Henry F. Krous, M.D.; Linda J. Lopez, B.S.N., R.N., Sr.P.H.N.; Dylan Ochal, M.S.IV; Theresa Rickard-Tibbett; Irma Riley, (*by telephone*); and Jeri Wilson, M.S.W.

- The meeting was held in person at the Embassy Suites Hotel in Glendale. All Council members were present. The meeting was called to order at 1:05 P.M., on November 18, 2015.

- **Introductions.**

Council members, state staff, and guests introduced themselves.

- **State Report.**

*Addie Aguirre, Carrie Florez, Mary Taylan and Guey-Shiang Tsay* reported on the California SIDS activities of the Maternal, Child, and Adolescent Health (MCAH) Division of the California Department of Public Health.

*Addie Aguirre*, Maternal, Child and Adolescent Health (MCAH) Assistant Division Chief and Title V Director gave a brief update on the MCAH Division Chief position: MCAH is working hard to recruit the MCAH Division Chief. The position is posted in the American Academy of Pediatrics website (<http://joburl.ws/7691578>) and National Healthcare Career Network website:

<http://www.nationalhealthcarecareernetwork.com/jobs?keywords=Public+Health+Care+Administrator+II&sort=>

Both sites go down on 2/17/16.

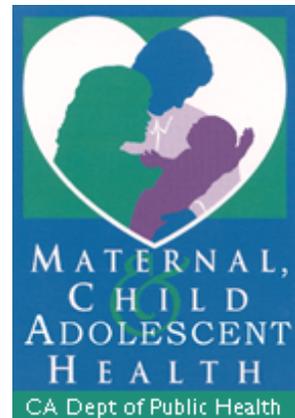
Annual California SIDS Conference: Thanks to the *Southern California Regional SIDS Council* and California State University at Sacramento *California SIDS Program* for organizing this year's SIDS Conference on 11/19/2015.

October 2015, was SIDS Awareness Month: The Director of the California Department of Public Health signed a letter in support of October, 2015, as SIDS Awareness Month (appended to these Minutes). The letter has been sent to our Local Health Jurisdictions and posted at the CDPH SIDS Program website:

<http://www.cdph.ca.gov/programs/SIDS/Documents/October%202015%20SIDS%20Awareness%20Month.pdf>

On behalf of MCAH, we thank Council for their contributions to the SIDS program. We also thank all of SIDS Coordinators and MCAH Directors for their ongoing efforts to promote infant safe sleep and SIDS risk reduction activities in their local health jurisdiction.

For 2016 SIDS Awareness Month in October, we suggest to coordinate with Council and local health jurisdictions to host a webinar to promote infant safe sleep and other SIDS related topics. There was additional discussion on this issue, and there was general agreement that the California SIDS Community should orchestrate some coordinated state-wide events to celebrate SIDS Awareness Month in October, 2016. All in attendance were asked to think creatively about what can be done.



California SIDS Program logo: We received approval from CDPH management to continue using the *California SIDS Program* logo on SIDS materials.

Infant Mortality Collaborative Improvement and Innovative Network (CoIIN) Update: MCAH continues to work with Alameda and Sacramento County to implement the Infant Mortality CoIIN Safe Sleep BIH Intervention at their county’s Black Infant Health program.

California SIDS Program Website: MCAH staff has been creating a new California SIDS Program website including most components of the current California SIDS Program. We are also working on



**Addie Aguirre      Mari Taylan-Arcoleo      Guey-Shiang Tsay      Carrie Florez**

rebuilding the portfolio information used by PHN/SIDS Coordinators and will post on the new website. This new website will be user friendly and will be maintained by the MCAH staff, which will make it easier to update and maintain. The new website will be available on the CDPH website this month. The current California SIDS Program website is also available in November.

Let’s Get Healthy California (LGHC): In 2012, Governor Brown issued Executive Order B-19-12 to create the *Let’s Get Healthy California Taskforce* with the goal of making California the healthiest state in the nation by 2022. The six LGHC goals areas are Healthy Beginnings, Living Well, End of Life, Redesigning the Health Systems, Creating Healthy Communities, and Lowering the Cost of Care. California Department of Public Health (CDPH) is very committed to implementing “*Let’s Get Healthy California*”. MCAH participates on taskforce with a focus on Healthy Beginnings. It is hoped that safe infant sleep and SIDS support and education can be included.

SUID/SIDS data: The 2013 statewide SUID/SIDS data has been submitted to Management for review and approval. Once MCAH receives approval, the data will be posted on the web.

*Doctor Keens* asked why these data need to be approved by “management” before they can be released, and if we could work on ways to speed up the process.

Reminder for Reporting/Documenting Sudden Unexpected Infant Death Cases ~ Coroner Notification Card, Public Health Services Reports, and other reporting documents need to be sent to CDPH/MCAH at:

Maternal, Child and Adolescent Health Division  
Attn: SIDS Program  
California Department of Public Health  
PO Box 997420, MS 8304  
Sacramento, California 95899-7420

• **California SIDS Program.**

Doctor Deborah Hunt, Susan Gonzalez, Kay Evans, and Mollie Mayer presented a report on the activities of the California SIDS Program.

California State University, Sacramento (Sac State) Team:

- Program Director – Deborah Hunt, Ph.D.: ([Deborah.Hunt@csus.edu](mailto:Deborah.Hunt@csus.edu))
- Nurse Educator – Kay Evans, RN, BSN, MA: ([evansk@csus.edu](mailto:evansk@csus.edu))



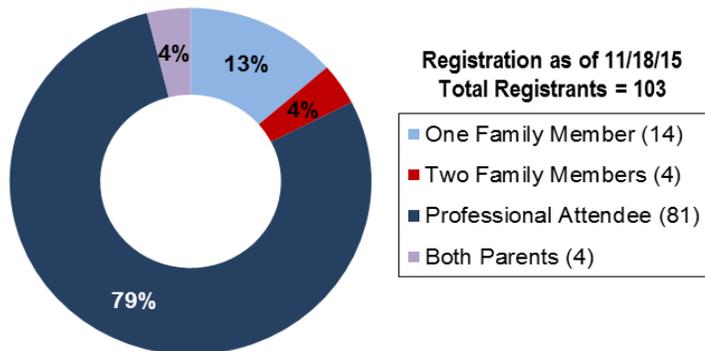
Deborah Hunt      Susan Gonzalez      Kay Evans      Mollie Mayer

Program Contact Information:

- SIDS Program toll-free line (1-800-369-SIDS (7437)) has been transferred to Sac State. The MOU between Sac State and Contra Costa Crisis Center has been signed and is in place. The Contra Costa Crisis Center is providing after hour, weekend, and holiday support to the SIDS toll-free line.
- CA SIDS Program email address: [CASIDSProgram@cce.sus.edu](mailto:CASIDSProgram@cce.sus.edu)

34<sup>th</sup> Annual Conference:

- Registration update (as of 11/18/15):
- The Sac State Team met with the Conference co-chairs, presenters, panel moderators, panel members, and the Welcome Reception organizers to identify needs and supports, which were captured in the detailed agenda.
- The following handouts will be available at the conference:



- 34<sup>th</sup> Annual California SIDS Conference Program Guide
  - Slides for Dr. Krous' presentation
  - The PHN's Role in Reducing the Risk of SIDS and SUID It's Not Just "Back to Sleep"
  - CDPH letter: Expansion of Referrals to Include Any Sudden, Unexpected Infant Death for Grief Support Services/New Coroner Notification Cards
  - AAP (2011): SIDS and Other Sleep-Related Infant Deaths: Expansion of Recommendations for a Safe Infant Sleeping Environment
  - Mitchell and Krous (2015). Sudden unexpected death in infancy: A historical perspective
  - Question Cards
- The conference online evaluation will be distributed to conference attendees on November 20, 2015. BRN/CEU certificates will be emailed directly to attendees after evaluation completion.

Additional Activities:

- General reminder that Coroner Notification Cards (CNCs) and other reporting forms (e.g., *Report of Contact* and *Public Health Services Report*) are to be sent to Carrie Florez at the CDPH.
- The California SIDS Program logo has been approved by CDPH for continuous use.
- Kay Evans has reviewed current SIDS Program resource materials and developed an inventory list. Please contact Kay Evans ([evansk@csus.edu](mailto:evansk@csus.edu)) if you would like to review the list or if you have any new material recommendations.
- The *PHN SIDS Coordinator Binder* is under review for updates. Please submit recommendations to Kay Evans ([evansk@csus.edu](mailto:evansk@csus.edu)).
- The Parent Packet and parent letter are under review. Please submit recommendations to Kay Evans ([evansk@csus.edu](mailto:evansk@csus.edu)).
- Spring Trainings
  - Northern California training to be held on April 14, 2016, in San Jose, CA.
  - Southern California training tentatively to be held on April 21, 2016, in Riverside, CA.
  - Sac State will be meeting with the Regional Council Presidents for training curriculum recommendations.
    - A request from the Northern CA Council was to invite a representative from CDSS to discuss the training offerings and requirements for Child Care providers.
    - Additional training topic suggestions should be sent to Kay Evans ([evansk@csus.edu](mailto:evansk@csus.edu)).
- Sac State looking into the feasibility of an Annual SIDS Coordinator meeting. Suggestions included:
  - Hold the meeting the day of the State Advisory Council in-person meeting
  - Hold the meeting the day after the annual conference
  - In addition, maybe hold specific training topic webinars
- CA SIDS Program would like to initiate conversation around coordination of activities for SIDS Awareness month (October 2016).
- Tentative date for the 35<sup>th</sup> Annual California SIDS Conference is October 6, 2016, in Richmond, CA.
- We wanted to bring to the attention of the SIDS community that the following billboard (Right) was seen in San Francisco, and we encourage you to notify your Regional SIDS Council, the California SIDS Advisory Council, the California SIDS Program, and CDPH if you see this billboard or any other similar misinformation.



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

**California State Coroners Association Meeting:** On September 23, 2015, Doctor Thomas Keens gave a presentation to the Annual Meeting of the *California State Coroners Association* at Lake Tahoe. He believes that his presentation went quite a ways toward establishing a collaborative relationship between the *California State Coroners Association* and the *California SIDS community*. He gave a 30-minute presentation to a plenary session of the meeting. The presentation reviewed basic SIDS demographics, ideas about current research focusing on the triple risk hypothesis, and a review of Hannah Kinney's research showing decreased serotonin in the brainstems of SIDS victims with or without evidence of an asphyxial contribution to the death. That those babies who die in the presence of some risk factors may have been predisposed to those deaths by brainstem problems was emphasized. He reviewed that most SIDS deaths now occur in the presence of 2-5 risk factors. He reviewed SIDS Summit I, emphasizing that in the minds of those making the diagnoses, SIDS, SUID, SUDI, and Undetermined all mean the same things. He then asked the Coroners for two favors. The first, that they refer all infants who died suddenly and unexpectedly to their local PHNs for education and grief support regardless of the diagnosis (SIDS, SUID, SUDI, Undetermined, Accidental, etc.). There were many nodding heads (positive) while he was describing the need for this. There appeared to be general agreement to this, and he hopes we will see an increase in referrals. His second request was that they complete death scene and autopsy protocols and send them to the state. This was not as readily agreed to. He had about 20-minutes of questions and discussion with a few coroners outside the room after his talk. It appears that this was successful.



Then, *Dennis Watt* and *Tom Keens* spoke informally to the managers of the CSCA for over an hour. They started by asking them for two favors. The first, to refer all families of infants dying suddenly (including SIDS, SUID, SUDI, Undetermined, and Accidental deaths) to their local public health nurses for education and grief support. There was general agreement about this. No real obstacles, so they are hopeful we will see more referrals. Everyone seemed to realize the importance of this.

They also asked them to complete Death Scene Investigation and Autopsy protocols, and submit them to the State. Data from 2013 indicate that only about 40% of Coroner notification cards are submitted to the State, and only about 8% of the Death Scene Investigation and Autopsy protocol forms were submitted. There was more discussion about this. Initial comments were that it took too much time and was not reimbursed. A number of issues came up. One was the Death Scene Investigation form itself. The form has not been revised in over a decade, and maybe it is time to look at it again. If the length or complexity of the form was such that it was preventing Coroners from completing it, we should look at that. *Dennis Watt* and *Tom Keens* offered to convene a group to look at this issue. One suggestion was also to include the death scene investigation protocol on the electronic death certificate system in the State. If it could be completed on line, this may facilitate completion of the forms. Some CSCA members would be expected to join a group to relook at this. There is no point doing this, as we did in the

beginning, with primarily researchers, and not having enough representation from the Coroner investigators in the trenches.

One issue that came up was the lack of feedback Coroners received from the State in terms of the data they have submitted. Coroners were told that the information they provide will be used to help with public health efforts and/or for research, but they have not seen evidence of this in the past. If Coroners complete the forms in greater numbers, they need to receive data promptly. It is reasonable for Coroners to receive feedback on the data they submit, and we will work with the State to increase data release promptly.

Another issue was that some PHNs who visit families tell them their baby died from SIDS even though the ultimate diagnosis may not be SIDS. The PHNs need some support and guidance from the California SIDS Program, and educating them on this and other issues could then occur.

*Doctor James K. Ribe* commented that it was his understanding, congruent with that of *Dennis Watt*, that regardless of whether state autopsy protocols are reimbursed, they are still mandated. That has been the assumption of the Los Angeles County Coroner Office. It appeared that many Coroners do not complete the death scene and autopsy protocols because the law only requires them to do this for babies dying from “SIDS” or “Presumed SIDS”. As many coroners predominately use other diagnoses (Undetermined, SUID, SUDI, accidental), they indicate that they do not have “SIDS” in their counties, and therefore do not need to comply. *Dennis Watt* has spoken preliminarily with the California State Sheriff’s Association about drafting legislation to change the law. The preferred new wording for completing of the protocols and referral to public health will be “Any infant, under 365-days of age, who dies suddenly and unexpectedly in whom a cause of death is not immediately apparent (includes but not limited to SIDS, SUID, SUDI, Undetermined, Asphyxiation, Strangulation, Entrapment) ...” . *Dennis Watt and Tom Keens* have drafted a Legislative Proposal to be reviewed by the California State Sheriff’s Association Legislative Committee. If they approve it, their legislative advocates will help get this into a bill, find sponsors, etc.

There was also a lot of interest and enthusiasm in SIDS Summit 2, currently in the planning stages.

Suggested action items based on the *California State Coroners Association* meeting:

- Coroners and medical examiners are encouraged to refer families of “Any infant, under 365-days of age, who dies suddenly and unexpectedly in whom a cause of death is not immediately apparent (includes but not limited to SIDS, SUID, SUDI, Undetermined, Asphyxiation, Strangulation, Entrapment)” to their local public health nurses so these families can receive SIDS/SUID education and grief support.
- It is time to review the Death Scene Investigation protocol form to see if the current questions are still relevant and/or if new questions should be added. A goal is to try and shorten or simplify the form.
- Ask Medical Examiners if the Autopsy protocol should be revisited. *Doctor Keens* is not aware of complaints from medical examiners about this form. So, if it is not broken, we need not fix it.
- *Dennis Watt and Tom Keens* will pursue to possibility of passing legislation to require coroners to refer families of “Any infant, under 365-days of age, who dies suddenly and

unexpectedly in whom a cause of death is not immediately apparent (includes but not limited to SIDS, SUID, SUDI, Undetermined, Asphyxiation, Strangulation, Entrapment)” to their local public health nurses, and to complete and submit death scene and autopsy protocols to the state.

**SIDS Summit 2:** The *California State Coroners’ Association* is in the process of planning the *SIDS Summit 2* conference. This will be an expansion of *SIDS Summit 1*, but will be interdisciplinary in order to fully explore the issues of diagnosis of infants dying suddenly and unexpectedly. This was discussed at a meeting of the *Coroners Curriculum Development Committee* in Orange County on June 25, 2015. Present plans are for this to be a 1½-day independent conference, probably in Marin County, and probably in the Spring of 2017. Plans include an in depth review of a baby who died suddenly and unexpectedly, with all persons involved in the case presenting their role. The second day will focus on all attendees struggling with the diagnosis and manner of death for a number of cases

- **Public Health Nurse Issues.**

The main public health nurse issue is that in many counties, only infants who die with a diagnosis of “SIDS” are being referred by Coroners/Medical Examiners to public health nursing for home visits to provide grief counseling and education. Infants with diagnoses of SUID, SUDI, Undetermined, etc., are not always being referred. The current law requires that infants who are presumed to have died from SIDS must be referred to public health. However, some counties do not make these referrals if the presumptive diagnosis is not SIDS.

Penny Stastny stated that this problem has priority for SIDS Coordinators in all LHJs. It was agreed that the new coroner notification cards and letters should eventually lead to an improvement in these referrals, and that the future SIDS Summit II should as well, but that more immediate measures should be taken. This includes working at the local LHJs between the SIDS Coordinators and the Coroner’s offices in order to give specific information on how to make referrals. One of the SIDS Coordinators has quarterly meetings with the Coroner Liaison and the SIDS PHNs to specifically discuss SIDS cases.

*Dennis Watt* described a baby death that occurred in the child care setting at Child Death Review. The child care provider had not received recent training. There is no mandated updated training in SIDS, and he explained how child care providers are not required to have SIDS training very often in California. Based on a recent court appearance in a child care license revocation case, it appeared to *Doctor James K. Ribe* that some licensed day care providers, especially ones who were licensed a long time ago, lacked awareness of safe sleep practices. *Lucy Chaidez* added that the current law requires only *one person* per child care home or center to have SIDS training (as part of a larger prevention-focused training with many topics), and then only *once in a lifetime*. Therefore, *most* child care providers in the state *are not required to have prevention, including SIDS, training*. And, of those who have had the training in the last 25 years, very few would have received training that includes the most recent Safe Infant Sleep guidelines (due to the fact that prevention training is not required to be repeated). Also, the one person who has the SIDS training does not necessarily have to be on-site with the children when they are in care. That means that in our state, there are probably thousands of babies sleeping in child care settings in which their providers do not have the latest SIDS prevention training.

AB 1207 was signed by the Governor on October 1, 2015, and will begin January 2018. It will require all child care providers to have SIDS training, in addition to child abuse mandated reporter training. The new law targets *all employees of licensed child care facilities, which includes centers and homes*. The *Office of Child Abuse Prevention* within the Department of Social Services will be in charge of developing the online training. The Child Care Law Center sponsored the new legislation.

- **SIDS Parent Issues.**

There was no discussion of parent issues.

- **Southern California Regional SIDS Council.**

*Penny F. Stastny, R.N., B.S.N., P.H.N.*, President of the Southern California SIDS Council, reported on the activities of the Southern California Regional SIDS Council.

The last meeting of the Southern California Regional SIDS Council was on November 12, 2015, at the offices of the *Guild for Infant Survival, Orange County* in Santa Ana.

The Southern California Regional SIDS Council is responsible for the 34<sup>th</sup> Annual California SIDS Conference, which will be held on Thursday, November 19, 2105, at the California Endowment Center in Los Angeles. The theme of the conference will focus on SIDS research in the morning, and SIDS parents training public health nurses in the afternoon.

Our Southern council has remained very dedicated and strong in members attending meeting both in person and online. The 34<sup>th</sup> annual

conference would not have happened without the collective and dedicated support of so many southern council members along with our new State SIDS Contractors from CSUS- Continuing Education College: Dr. Deb Hunt, Susan Gonzalez, Kay Evans and Claire Thompson. In just 4 ½ months CSUS have rolled up their sleeves, shared our vision for this conference and got the work done. I refer to them as the “awesome foursome”.

Our Southern Council has spent the last 2 years planning this conference which we hope everyone will find meaningful. We are very grateful to Dr. Henry Krous for being our keynote speaker addressing research into possible causes of SIDS. We also thank Dr. Keens who will address and review ways to reduce the risk of SIDS. Further, we hope this conference will be



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remembered for the passion and desire exhibited by many articulate SIDS parents as they share their tragic stories of their baby's deaths in hopes of helping us PHNs and other health professionals in the understanding that is necessary to then help the newly bereaved SIDS parents and caregivers. We hope that for you this conference will be an exciting, educational, enlightening and enriching day!!

We have addressed the details of the conference.

The Southern California Regional SIDS Council is responsible for the 34<sup>th</sup> Annual California SIDS Conference, which will be held on Thursday, November 19, 2105, at the California Endowment Center in Los Angeles. The Council has tentatively planned the following:

Wednesday, November 18, 2015 (Embassy Suites Hotel, 800 North Central Avenue, Glendale, California):

5:30-8:00 p.m. Welcome Reception, planned by SIDS parent groups in Southern California. We will serve simple finger foods, sweet and savory, iced tea and coffee and tea, per hotel minimum food purchase rules. There will also be a no host bar. It is our hope that this would be a peaceful evening for parents, a time to connect and not feel alone. We will provide name tags and simple decorations in blue and pink for the tables.

6:00 p.m. Memorial Service, planned by Michelle Herrera and the Guild for Infant Survival-San Diego. Parents will be invited to share a special memory or poem about their child. Slide show will immediately follow. We want the evening to be natural and free flowing. Those on the planning committee will wear different color name tags, so new parents will know who they can talk to if they need some support. Have use of the room until 8:30 p.m. Jeri Wilson and Lorie Gerhke will present.

Thursday, November, 19, 2015. 34<sup>th</sup> Annual California SIDS Conference (California Endowment Center, 1000 North Alameda Street, Los Angeles, California).

7:30-8:30 a.m.: Registration and continental breakfast.

8:30-8:45 a.m.: Introduction and Welcome to the Conference. *Penny F. Stastny, R.N., B.S.N., P.H.N.*, President of the Southern California Regional SIDS Council.

8:45-9:45 a.m.: "SIDS Research Update and How the Diagnosis of SIDS is Made". *Henry F. Krous, M.D.*, Professor of Pediatrics and Pathology Emeritus, University of California, San Diego, School of Medicine; 1999 Daniel E. Boatwright Awardee; 2012 Lifetime SIDS Achievement Awardee (California SIDS Advisory Council). He is confirmed for this talk.

9:45-10:15 a.m.: Break. Intentionally 30-minutes for networking.



**Penny F. Stastny and  
Danielle Sees.  
Co-Chairs, 34<sup>th</sup> Annual  
California SIDS  
Conference**

10:15-11:15 a.m.: “Safe Infant Sleep and SIDS Risk Reduction”. *Thomas G. Keens*, Professor of Pediatrics, Physiology and Biophysics, Keck School of Medicine of the University of Southern California; and Chair of the California SIDS Advisory Council.

11:15 a.m.-12:15 p.m.: Ask the Experts Panel, including: Doctors Krous, Keens, and Ribe, Kitty Roche, and Dennis Watt. Danielle Sees will moderate.

12:15-12:30 p.m.: The presentation of the *2015 Daniel E. Boatwright Award* by Tom Keens

12:30 – 1:30 p.m.: Lunch provided at the California Endowment Center.

1:30-2:45 p.m.: SIDS Parents tell us what they need, How to say it, What to do and What not to do, etc. A panel of SIDS parents will make this presentation. The panel will consist of: *Rachel Strickland, Kris Concepcion, Maureen Rubalcaba, Christina Thiele, and Alicia Bratcher*. The panel will be facilitated by *Penny Stastny*. Penny has had a conference call and other communication with the parents, and she is confident that this will be an important session.

2:45-3:15 p.m.: Break. Intentionally 30-minutes for networking.

3:15-4:15 p.m.: Concurrent Sessions:

**Public Health Nurses provide tips on SIDS Home Visits.** The panel will be facilitated by *Kitty Roche*, and it will consist of *Deja Castro, Danielle Sees, and Penny Stastny*. Kitty introduces herself. Brief explanation of how SIDS referrals have changed in the last 10 years in California: budget cuts, frequent turnover of SIDS Coordinators, death diagnoses, etc. I will then introduce the vignette that demonstrates what possible system gaps may occur with the changes (approx. 3 minutes)

Penny: 5 minutes to do vignette

Kitty will then begin the panel discussion asking for brief introductions that include your name, title, LHJ for whom you work and perhaps how many referrals you receive in a year or so. After introductions, I will begin the questions. (Approx. 5 minutes total)

1. As the impacts have occurred in your LHJ, in what ways have you had to adapt to meet the needs of your SIDS clients
  - Kitty will introduce the topic by discussing having a relationship with the ME (maximum 5 minutes)
  - Cynthia – talk about what happens when you receive a referral (nitty gritty of making contact, etc.) and walk us through your process. It would be great if you could include some of the challenges you face with a diverse population.(Max. 5 minutes)
  - Deja - please focus on the packet you devised starting from when you first receive the referral (and how you get them). (Maximum 5 minutes)
  - Danielle – The importance of referring families for Peer Support (Maximum 5 minutes)
  - Penny – discuss home visiting in terms of meeting parent needs and not just gathering data for reports (Maximum 5 minutes)
2. What have you found to be your most successful strategy in engaging clients? Please be specific. (2 minutes each)
3. Questions from the audience

SIDS Parents Support Group to be facilitated by *Maureen Rubalcaba and Rachel Strickland*. *Rachel Strickland* will lead grandparent group (breakout room not needed) *Maureen* was suggested to lead parent group.

4:15-4:30 p.m.: Closing Slide Show of SIDS Babies, and Closing Comments. Slide show will be shown and *Rachel* and *Michelle* will invite parents to come up and say babies name and receive the angel key chain. Key chains for moms, dads and grandparents will be available for those in attendance. Angel craft -- *Rachel Strickland* has a friend who is willing to make each SIDS parent a lovely memento of the conference. These will be presented at the end of the conference.

#### Community Reports Highlights:

- ***Doctor Thomas G. Keens*** gave the following presentations:
  - 08/20-21/15: “Sudden Infant Death Syndrome: Probing the Medical Mystery: Science, Public Health, and Impact on Families”. *With Danielle Sees, Rachel Strickland, and Christina Thiele*. Freshman Welcome Week Microseminar. University of Southern California. Los Angeles, California.
  - 09/23/2015: “Sudden Infant Death Syndrome”. Annual Meeting. California State Coroners’ Association. Lake Tahoe, California.
  - 09/25/2015: “Sudden Infant Death Syndrome”. Grand Rounds. Mercy Medical Center Redding. Redding, California.
  - 10/02/2015: “Safe Infant Sleep: Reducing the Risk of SIDS and Sudden Unexpected Infant Death”, *with Danielle Sees*. **Regional Perinatal Program for the South Coast Region**. Miller Family Health Education Center. Long Beach, California.
- ***City of Long Beach (Danielle Sees)***:  
On October 2, 2015 Dr. Keens and I presented to a group of 45 + nurses from local hospitals on Safe Infant Sleep and SIDS research.
- ***Orange County (Penny F. Stastny)***:  
11-6-2015 **Resubmitted manuscript** “Supporting SIDS Families: The Public Health Nurse SIDS Home Visit” – to the *Public Health Nursing* journal with reviewer’s recommended suggestions.
- ***Guild for Infant Survival, Orange County (Barbara Estep)***:  
*April 4, 2016*, we are planning a luncheon fundraiser at the historical *Anaheim White House Restaurant*. This is a big endeavor and we hope all who are able will support the Guild.  
*Parent Support meetings continue monthly. November 9<sup>th</sup>; December 12<sup>th</sup>, 2015.*  
*December 6, 2015, is the 14<sup>th</sup> Anniversary of the “Angel of Hope” Candlelight Service* at El Toro Memorial Park. We invite each of you, and any family who has lost a child for any reason. The service is one hour long from 7:00pm to 8:00pm. There is ample parking and no charge. A flyer is appended to these Minutes.
- ***Orange County (Linda Lopez)***:  
10/29/2015: OC Health Care Agency 3 hour training “The Role of the PHN in Reducing the Risk of SIDS and SUID: It’s not Just ‘Back to Sleep’”. *With Dr. Tom Keens, Penny F. Stastny and Rachel Strickland*. Public Health Nurse Education Conference. Over 100 PHNs attended. California SIDS Program contractors *Deborah Hunt and Kay Evans*

attended along with two PHNs from Riverside County. OC Coroner's Investigator Tiffany Williams also came to training. Setting up date to meet with Linda and Penny to foster better referral system between OCHCA and Coroner's office.

- ***San Diego County (Kitty Roche):***  
Among all 6 regions and presenting to 4 different Schools of Nursing – 75 students. Writing Home Visit Protocols for SIDS Home Visits specific to San Diego County. Completing Standard Orientation protocol for PHNs newly placed as the SIDS PHN. Revising standardized Ppt. for Professional and Community presentations.
- ***County of Riverside (Deja Castro):***  
10/16/2015: Riverside Community College 80 RN students attended a SIDS presentation
- ***Los Angeles County Office of Coroner (James K. Ribe):***  
Due to administrative problems, the time delay of reporting of toxicology results at the Coroner's Office has increased from three weeks to several months. This has impacted the time to complete SIDS reports.  
It is our subjective impression that the number of SIDS cases has decreased in the past year. Investigator Bertone and I are in the process of quantitating this.
- ***Los Angeles County Parent Grief Support Group (Christina Thiele):***  
Over the last few months, I have seen a drastic increase in attendance from not only parents but family members as well. I attribute this to the holiday season and a growing need for support. . A few parents and I have been talking about starting a Los Angeles Guild for Infant Survival. With the help of my "lawyer brother" that will hopefully take place next year with several of the parents from our group. Our goal is to be of service to more parents. Christina Thiele ([Christina23thiele@gmail.com](mailto:Christina23thiele@gmail.com); 707-849-5347).

The following *officers were elected for the Southern California Regional SIDS Council* to serve January 1, 2016, through December 31, 2018:

- President: Kitty Roche, R.N., P.H.N., B.S.N., M.S.W.
- Vice President: Maureen Rubalcaba.
- Secretary: Christina Thiele.

The *meetings of the Southern California Regional SIDS Council for 2016*, were established as:

- Thursday, February 11, 2016.
- Thursday, May 12, 2016.
- Thursday, August 11, 2016.
- Thursday, November 10, 2016.

The meetings will be held at the offices of the *Guild for Infant Survival, Orange County*, in the Olive Crest Building, 2130 East Fourth Street, Suite 125, Santa Ana, California 92705.

- **Northern California Regional SIDS Council.**

*Susana Flores, P.H.N.*, President of the Northern California Regional SIDS Council, reported on activities of the Northern California Regional SIDS Council.

Since Our last meeting in August, this group has met twice. Once in September 18, 2015, and the last meeting was this past Friday November. 13, 2015. Our September meeting was about getting to know our new contractors, who I believe are doing a great and awesome job in

helping us all work together collectively, and helping us to clarify the communication among all of the regions from this state.

On our September 18<sup>th</sup> meeting, Julie Garcia from Alameda County brought up the issue that Alameda County has to deal with child care centers being held accountable for safe sleep guidelines. Natalie Berbeck, Social Worker from Contra Costa, brought up the idea that we can have a representative from Community Care Licensing coordinate. What current requirements for licensed day care providers will be looked into by CSUS Contractors.

A while back, I brought up the issue of reviewing the letter head and rewriting the letters that go out to parents, child care centers, etc after a SIDS/SUID death or a presumed SIDS/SUID death has occurred. We have talked about this previously and I am glad to hear that we are moving in the right direction in beginning to do the work that needs to be done now that the CSUS contractors are working on updating the website alongside the state; especially, now that we have a new approved logo.



**Northern California Regional SIDS Council,  
November 15, 2013.**

At this past meeting on Friday, November 13<sup>th</sup>, this group voted for new officers. I am pleased to announce that Natalie Berbeck Social Worker from Contra Costa has accepted this new role. Lorie Gehrke will continue to be the Vice President and Marie Joy Supapo, SIDS Coordinator for Solano County graciously accepted to continue her role of secretary.

San Francisco County SIDS Coordinator, Ailine Armstrong, shared about the team of doctors that are planning to meet on December 7, 2015, to do a case review for SUID cases reported in the past 5 years. I know that this is a conversation that was initiated via email in an effort to improve communication, and it sounds like Dr. Curtis Chang, Dr. of SF MCHA and Dr. Christopher Stewart, UCSF Pediatrician are now aware of the SIDS council task force to collaborate together on this.

These were main issues brought up in the North. I would like to now share with you the dates for the Northern Calif. Regional SIDS Council meetings in 2016: February 19, April 22, June 17, Sept 9 and the last one will be Nov. 18, 2016. All meetings are held from 9:30 -12:30 at the Contra Costa Crisis Center in Walnut Creek.

This concludes my service as the President of the Northern California Regional SIDS Council. It has been a pleasure working with you all at this level. I am sure that Nicole will do a great job in her new role as the President of this region. She has a lot of passion and creative ideas in her effort to bring awareness about SIDS risk reduction. Thank you

- **California SIDS Advisory Council Membership.**

- *Kitty Roche* has served as Secretary for the *California SIDS Advisory Council* for the last several years. However, she is the incoming President of the *Southern California Regional SIDS Council*, and therefore asked to resign as Secretary. *Lorie Gehrke*, the Vice President of the *California SIDS Advisory Council*, volunteered to take on the role of Secretary, in addition. The *Council* is grateful that she volunteered for this. The *Council* expressed its thanks and gratitude to *Kitty* for serving as Secretary all of these years.



Kitty Roche

Lorie Gehrke

- *Penny Stastny* and *Susana Flores* have served as Presidents of the Southern California Regional SIDS Council and Northern California Regional SIDS Council respectively for the past 3-years. In their roles as President, they have also served as ex-officio members of the *California SIDS Advisory Council*. Their terms as Presidents of their respective Regional SIDS Councils end on December 31, 2015. The *Council* appreciates the hard work, dedication, expertise, and commitment of both *Penny* and *Susana*, and thanked them for their service. The *Council* invited and encouraged both *Penny* and *Susana* to remain active in activities of the *California SIDS Advisory Council*.



Penny Stastny Susana Flores

- Beginning in 2016, the new Regional SIDS Council Presidents will serve as ex-officio members of the *California SIDS Advisory Council*. The incoming Southern California Regional SIDS Council President, *Kitty Roche*, is already an appointed Public Health Nurse member of the *Council*. The incoming Northern California Regional SIDS Council President, *Natalie V. Berbick*, will join the Council for the duration of her term.

- **2016 International Conference on Stillbirth, SIDS, and Baby Survival.**

2016 International Conference on Stillbirth, SIDS, and Baby Survival: will be held at the Raddison Victoria Plaza Hotel in Montevideo, Uruguay, on September 7-10, 2016. This conference is sponsored, in part, by the International Society for the Study and Prevention of Infant Death.



• **2016 California SIDS Advisory Council Meetings.**

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 Council meetings in 2016, will be as follows:

- Tuesday, January 19, 2016; 1:30-3:30 p.m. via telephone Conference Call.
- Tuesday, April 19, 2016; 1:30-3:30 p.m. via telephone Conference Call.
- Tuesday, August 16, 2016; 1:30-3:30 p.m. via telephone Conference Call.
- In person meeting, Wednesday, October 5, 2015, 1:00-4:00 p.m. in Richmond, California. This will be the day before the 35<sup>th</sup> Annual California SIDS Conference.

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 4:06 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



---

 **California SIDS Advisory Council** 



**Kathleen  
Beichley**



**Kris  
Concepcion**



**Dawn  
Dailey**



**Lorie  
Gehrke**



**Tom  
Keens**



**James  
Ribe**



**Kitty  
Roche**



**Rachel  
Strickland**



**Dennis  
Watt**



**Penny  
Stastny**



**Susana  
Flores**



KAREN L. SMITH, MD, MPH  
Director and State Health Officer

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



EDMUND G. BROWN JR.  
Governor

### October is Sudden Infant Death Syndrome Awareness Month

In California, 269 infants died suddenly and unexpectedly in 2013, with most deaths occurring when the infant was sleeping. The Centers for Disease Control and Prevention refer to sleep-related deaths as Sudden Unexpected Infant Deaths (SUID). Sudden Infant Death Syndrome, or SIDS, is one of three sleep-related causes of death. SIDS is defined as the sudden death of an infant who is less than one year of age that is unexpected and cannot be explained after a thorough case investigation including a complete autopsy, examination of the death scene, and review of the infant's clinical history.

In 2013, 157 infants less than one year of age died of SIDS in California, making it the second leading cause of mortality for infants between 28 days of age to less than one year of age. Despite years of research, the exact cause(s) of SIDS remain unknown. To help reduce SIDS and other sleep-related deaths, the California Department of Public Health's (CDPH) endorses the 2011 American Academy of Pediatrics recommendations to educate parents and the public about placing babies to sleep on their backs. Other risk reduction messages include placing babies on a firm sleep surface, room-sharing without bed-sharing, breastfeeding, never smoking around the baby, not letting a baby overheat during sleep, keeping soft objects out of a baby's sleep area, receiving immunizations and regular well-child checks. These important infant safe sleep messages have helped reduce the incidence of SIDS and other sleep-related deaths.

During the month of October, CDPH, SIDS Advisory Council, and California's 61 local health jurisdictions (LHJs) promote SIDS Awareness through a variety of outreach events. These efforts are part of an ongoing campaign to increase public awareness about SIDS and other sleep-related deaths and infant safe sleep practices. California has earned a national reputation for excellence in SIDS education, risk reduction campaigns, and grief and bereavement support services.

This October, I commend the efforts made by the CDPH, SIDS Advisory Council and the LHJs in promoting infant safe sleep practices, and SIDS risk reduction activities.

Sincerely,

A handwritten signature in blue ink that reads 'Karen L. Smith'.

Karen L. Smith, MD, MPH  
Director and State Health Officer  
California Department of Public Health



KAREN L. SMITH, MD, MPH  
Director and State Health Officer

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



EDMUND G. BROWN JR.  
Governor

DATE: JULY 31, 2015

TO: COUNTY CORONERS, SHERIFF CORONERS AND MEDICAL EXAMINERS

SUBJECT: EXPANSION OF REFERRALS TO INCLUDE ANY SUDDEN, UNEXPECTED INFANT DEATH FOR GRIEF SUPPORT SERVICES/NEW CORONER NOTIFICATION CARDS

When an infant dies suddenly and unexpectedly, the need for the family to receive grief support is crucial. Currently, California Health and Safety Code §123740 requires local health jurisdictions (LHJ) contact persons having custody and control of the infant who experienced a presumed Sudden Infant Death Syndrome (SIDS) death and provide grief support services. LHJs rely on referral of any sudden, unexpected infant death from their local coroner or medical examiner's office to be able to contact families and provide support services.

The intent of this letter is to ask coroners and medical examiners to voluntarily refer to their LHJ the death of any infant who dies suddenly and unexpectedly, regardless of the sleep environment at the time of death. This would include voluntary referral of deaths that may receive an 'unknown' or 'undetermined' diagnosis, as well as, deaths where risk factors in the sleep environment may lead to a diagnosis of 'asphyxia', 'positional or mechanical asphyxia', or 'probable overlay'. The California SIDS Advisory Council recommends any person interacting with families who may receive one of these diagnoses be provided the same grief support as a family who receives a SIDS diagnosis.

Collaboration between the coroner or medical examiner office and their LHJ 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 grief is critical and beneficial. We thank you for your continued referrals of sudden, unexpected infant deaths, even with the continued suspension of the state mandates due to state budget constraints.

Enclosed are new, blue, Coroner Notification Cards (CNC) for you to use. Please do not use the yellow CNCs as the account set up to receive those cards has closed. We

COUNTY CORONERS, SHERIFF CORONERS AND MEDICAL EXAMINERS  
July 31, 2015  
Page 2

appreciate your continued support sending completed CNCs, which now will be sent to the Maternal, Child and Adolescent Health Division at the California Department of Public Health.

We look forward to continuing to work with you. 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). For questions specific to the CNC, please contact Carrie Florez, Research Scientist, at [Carrie.Florez@cdph.ca.gov](mailto:Carrie.Florez@cdph.ca.gov) or (916) 650-0323.

Sincerely,



Addie Aguirre  
Acting Division Chief

Enclosures

cc: MCAH Directors, SIDS Coordinators

**CALIFORNIA SUDDEN INFANT DEATH SYNDROME (SIDS) PROGRAM  
CORONER'S NOTIFICATION CARD**

The California SIDS Program appreciates your efforts to help us track sudden, unexpected infant deaths in California through the Coroner's Notification Card. This reporting system permits the indexing of all cases in which the provisional cause of death is *SIDS, sudden death in infancy, sudden unexplained death, sudden unexplained infant death, sudden infant death, unknown/undetermined, asphyxia, positional/mechanical asphyxia, or probable overlay.*

The California SIDS Program, along with the State SIDS Advisory Council, recommends families who receive any of the above diagnoses are provided the same grief support services.

Pursuant to Health and Safety Code, Section 462, families who receive a SIDS diagnosis are to receive grief support services from their local public health department. Please consider voluntarily referring any sudden, unexpected infant death to the local public health department in the infant's county of residence within 24 hours, or as soon as possible after the gross autopsy.

**Thank you for your cooperation in completing this card. If you have any questions or need additional information, please call (916) 650-0323.**

_____ INFANT'S LAST NAME                      FIRST                      M. INITIAL			_____ SEX
_____ STREET ADDRESS			____/____/____ DATE OF BIRTH
_____ CITY	_____ STATE	_____ ZIP	BORN IN CALIFORNIA? <input type="checkbox"/> YES <input type="checkbox"/> NO
_____ COUNTY OF RESIDENCE			____/____/____ DATE OF DEATH
_____ MOTHER'S LAST NAME                      FIRST                      M. INITIAL			_____ COUNTY OF OCCURRENCE OF DEATH
_____ FATHER'S LAST NAME                      FIRST                      M. INITIAL			____/____/____ DATE REPORTED TO HEALTH DEPARTMENT IN COUNTY OF RESIDENCE
_____ CORONER'S CASE NUMBER			

**(DO NOT STAPLE)  
PLEASE FOLD, TAPE TO SEAL,  
AND MAIL TO  
ADDRESS ON BACK.**

	<p><b>Thursday, November 19, 2015</b> <b>8:30 a.m.-4:30 p.m.</b> <b>California Endowment Center</b> <b>1000 North Alameda Street</b> <b>Los Angeles, California</b></p>	
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# 34<sup>th</sup> Annual California Sudden Infant Death Syndrome Conference



Featuring

**Professor Henry F. Krous**

Professor of Pathology Emeritus, UCSD  
Rady Children's Hospital of San Diego

**“Sudden Infant Death Syndrome Research”**

## Program Description

This Program is designed to give Public Health Nurses, SIDS families, and others, an understanding of SIDS, latest research into causes, ways to reduce the risk, how PHNs provide education and grief counseling to SIDS families, and hear the personal story of SIDS parents.



**For more information and to Register, contact:**

<http://www.cvent.com/events/34th-annual-california-sids-conference/event-summary-b0affb01385042239c5b9c8ce5e3aafb.aspx>

**34<sup>th</sup> Annual California SIDS Conference**  
*California Endowment Center*  
*1000 N Alameda Street, Los Angeles, CA*  
*Yosemite Room*

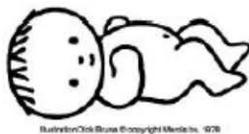
**Agenda**

*November 19, 2015*

*7:30 a.m. - 4:30 p.m.*

- |                            |  |
|----------------------------|--|
| <i>7:30 am - 8:30 am</i>   | <i>Registration and Continental Breakfast</i>  |
| <i>8:30 am - 8:45 am</i>   | <i>Welcome Remarks</i><br><b>Penny F. Stastny</b>  |
| <i>8:45 am - 9:45 am</i>   | <i>Keynote: SIDS Research Update and How the Diagnosis of SIDS is Made</i><br><b>Henry F. Krous, MD</b>  |
| <i>9:45 am - 10:15 am</i>  | <i>Networking Break</i>  |
| <i>10:15 am - 11:15 am</i> | <i>Safe Infant Sleep and SIDS Risk Reduction</i><br><b>Thomas G. Keens, MD</b>   |
| <i>11:15 am - 12:15 pm</i> | <i>Panel Presentation: Ask the Experts</i><br>Moderator: <b>Danielle Sees</b><br>Panel: <b>Thomas G. Keens, MD; Henry F. Krous, MD; James Ribe, MD; Kitty Roche; and Dennis Watt</b>   |
| <i>12:15 pm - 12:30 pm</i> | <i>2015 Daniel E. Boatwright Award</i><br>Presented By: <b>Thomas G. Keens, MD</b>   |
| <i>12:30 pm - 1:30 pm</i>  | <i>Lunch at the California Endowment Center</i>  |
| <i>1:30 pm - 2:45 pm</i>   | <i>Plenary Session: SIDS Parents Tell All</i><br>Moderator: <b>Penny F. Stastny</b><br>Panel: <b>Alicia Bratcher, Kris Concepcion, Maureen Rubalcaba, Rachel Strickland, Christina Thiele</b>                                |
| <i>2:45 pm - 3:15 pm</i>   | <i>Networking Break</i>  |
| <i>3:15 pm - 4:15 pm</i>   | <i>Breakout Sessions:</i> <ul style="list-style-type: none"><li>• <i>Parent Session: SIDS Parents Support Group</i></li><li>• <i>Public Health Nurse: Tips on SIDS Home Visits by and for Public Health Nurses</i></li></ul> |
| <i>4:15 pm - 4:30 pm</i>   | <i>Closing Ceremony</i><br><b>Danielle Sees</b><br><b>Rachel Strickland</b>  |

## The 2016 International Conference on Stillbirth, SIDS and Baby Survival (ISA/ISPID Congress)



*Joining efforts to reduce perinatal and infant mortality in Latin America*



**Date: 8-10 September, 2016**

Preconference: September 7, 2016

Location: Radisson Victoria Plaza Hotel  
Montevideo, Uruguay

### Sponsors

