



California Sudden Infant Death Syndrome Advisory Council

Minutes of the May 3, 2016, Meeting

By Telephone Conference Call.

Members of the Council

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

Lorie Gehrke, Vice Chair,
SIDS Parent.

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.

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

Rachel Strickland, SIDS
Parent.

Dennis H. Watt, Coroner.

Kitty Roche, R.N., P.H.N.,
B.S.N., M.S.W.,
President, Southern Calif.
Regional SIDS Council.

Natalie V. Berbick, M.S.W.,
President, Northern Calif.
Regional SIDS Council.

Council Chairperson:

Thomas G. Keens, M.D.
Division of Pediatric
Pulmonology
Children's Hospital Los
Angeles
4650 Sunset Boulevard,
Box #83
Los Angeles, California
90027-6062
Phone: 323/361-2101
FAX: 323/361-1355
E-mails:

tkeens@chla.usc.edu
tkeens@gmail.com



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

- **Members Present:** Thomas G. Keens, M.D., *Chair*; Lorie Gehrke, *Vice Chair*; Natalie V. Berbick, M.S.W.; Kris Concepcion; Dawn Dailey, R.N., P.H.N., Ph.D.; James K. Ribe, M.D., J.D.; Kitty Roche, R.N., P.H.N., B.S.N., M.S.W.; and Dennis H. Watt.
- **Members Absent:** Kathleen Beichley; Rachel Strickland.
- **State and California SIDS Program:** Kay Evans, R.N.; Carrie Florez; Deborah L. Hunt, Ph.D.; and Mollie Mayer.
- **Guests:** Cheryl Assante, R.N., P.H.N., B.S.N.; Lucy Chaidez; Terrie Davis, R.N.C.P., B.S.N., P.H.N.; Natalie Dunaway; Sally Eberhard, P.H.N.; Brenda Harris, R.N., P.H.N.; Michelle Herrera; Lucia Kang; Joan La Porte, P.H.N.; Tracy Osterday, B.S.N., P.H.N.; Shelley Parker; Stephany Ponce, R.N., P.H.N.; Danielle Sees, B.S.N., R.N., P.H.N., C.L.E.; Penny Stastny, R.N., B.S.N.,

P.H.N.; Theresa Tibbett, C.E.S.; and Laurel Waters, M.D., F.C.A.P., F.A.S.C.P.

- **Alternate Council Members:** In accordance with the Standing Rules of the California SIDS Advisory Council:
 - *Michelle Herrera* was designated as an alternate for *Rachel Strickland*, who could not attend today's meeting.
 - The meeting was held by telephone conference call. A quorum of greater than 2/3 of Council members was present. The meeting was called to order at 1:31 P.M., on May 3, 2016.¹

- **Introductions.**

Council members, state staff, and guests introduced themselves.

- **In Memorium.**

Doctor Shirley Tonkin a renowned and pioneering SIDS researcher from New Zealand died on January 27, 2016. She was the first to suggest that babies sleeping on their stomachs was dangerous. She made this observation and recommendation as early as 1972. However, she was a lone voice for decades before her ideas took root with the international SIDS community. I met *Doctor Tonkin* at a number of SIDS research conferences, where I always found her to be warm and gracious.



Dr. Shirley Tonkin John Mack

John Mack a SIDS parent, activist, and Daniel E. Boatwright Award recipient in 2007, died on January 26, 2016. He was a fierce advocate for SIDS parents, especially in central California, where he established SIDS parent support. He served on the Northern California Regional SIDS Council, spoke at many SIDS conferences and trainings, and generally did whatever he could to help the California SIDS community.

Natalie Berbick suggested that members of the California SIDS Community who have died in the previous year be acknowledged at the Annual California SIDS Conference each year. There was a consensus that this would be a good idea.

- **State Report.**

Carrie Florez reported on the SIDS activities of the Maternal, Child, and Adolescent Health (MCAH) Branch of the California Department of Public Health.

¹ Many terms are used to describe babies who die suddenly and unexpectedly during sleep in whom the cause can not be determined. These terms include SIDS, SUID, SUDI, Undetermined, and some Accidental diagnoses. In these Minutes, the term "SIDS" or "Sudden Infant Death Syndrome" will be used to describe all of these babies. These terms all mean the same thing: the death was *unexpected* and *unexplained*.

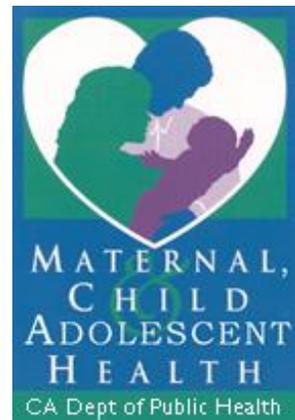
Thanks to the presenters, SIDS Councils, and CSUS SIDS Contractor for their efforts to provide the SIDS Trainings to Emergency Personnel and Public Health Professionals.

When MCAH requested to reserve the conference rooms for the 35th Annual California SIDS Conference at the state facility in Richmond for October 6, 2016, we were informed that the auditorium was already booked on October 6. MCAH made the request to reserve both the Richmond and Sacramento state facilities on October 13 and 14, and the Northern CA regional SIDS Council chose the conference location in Sacramento.

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 BIH program. MCAH will conduct the feedback session with the State and local BIH staff and local BIH participants in May and June and this project will end at the end of June, 2016.



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



• **California SIDS Program.**

Doctor Deborah Hunt and Kay Evans presented a report on the activities of the California SIDS Program.

2016 Annual Conference

- Provided a facility site search analysis to the Northern California Regional SIDS Council to review and consider in determining the 35th Annual California SIDS Conference dates and location. Conference to be held on October 14, 2016, in Sacramento (1500 Capitol Avenue, Sacramento, 95814)

California SIDS Program



Deb Hunt Kay Evans Mollie Mayer Susan Gonzalez

- Developed an online survey to poll the Northern California Regional SIDS Council members regarding recommended presenters and topics. The survey closes on May 11, 2016.
- We are working on securing a room block at the: Hyatt Regency Sacramento 1209 L Street Sacramento, CA 95814

California SIDS Trainings for Emergency Personnel and Public Health Professionals 2016:

- Delivered two trainings – San Jose (04/14/2016) and Moreno Valley (04/21/2016).
- We would like to acknowledge and thank the following presenters and curriculum development team members: Natalie Berbick, Deja Castro, Susana Flores, Carrie Florez, Lorie Gehrke, Dr. Tom Keens, Kitty Roche, Danielle Sees, Penny Stastny, Guey-Shiang Tsay, Dennis Watt, and Jeri Wilson.
- We received very positive verbal feedback at the conclusion of both trainings.
- The online California SIDS Training Evaluation: Closed on April 29, 2016, for the San Jose training. Closes on May 6, 2016, for the Moreno Valley training.
- Final attendee numbers were: San Jose, CA: 111 attendees, Moreno Valley, CA: 114 attendees
- Please submit suggestions for the 2017 training locations to the California SIDS Program.

Additional Activities

- We met with the California Department of Social Services, Community Care Licensing Division to discuss the role and potential participation of the Child Care advocates and analysts.
- We met with the CCLD Child Care Advocates via conference call and discussed their availability and participation in the Spring 2016 trainings.
- The following CCLD Child Care Advocates participated in the 2016 Spring trainings: Natalie Dunaway (Northern CA Advocate), Roberta Williams (Central CA Advocate), and Aaron Ross (Southern CA Advocate).
- Potential Annual SIDS Coordinator Meeting: Tentatively to be held the day before the Annual Conference. Please submit your name to the California SIDS Program if you are interested in volunteering to work with the California SIDS Program and CDPH representatives in developing the agenda and content.
- **SIDS Awareness and Safe Sleep Education Day:**
 - The *California SIDS Program* established a SIDS Awareness Month Planning Committee to help generate ideas for the coordination of statewide activities in October, 2016. The following people volunteered: Erica Alexander, Luz Arboleda-Babcock, Lucy Chaidez, Michelle Herrera, Kitty Roche, Danielle Sees, and Rachel Strickland.



- The California SIDS Program is awaiting CDPH approval and clarity of the Program's role in participating in the activities. Currently, the day before the 35th Annual California SIDS Conference is an option for activities to be held on the State Capitol steps.

Personnel Changes:

- Claire Thompson is no longer with the California SIDS Program.
- Please direct communication to: CASIDSProgram@cce.csus.edu or 1-800-369-SIDS(7437).
 - Deb Hunt: Deborah.Hunt@csus.edu
 - Kay Evans: EvansK@csus.edu

Council Requests of the California SIDS Program

- Resume the Peer Contact Training
- Create a list and/or central repository of standardized and approved grief and informational materials that have been vetted with the California SIDS Advisory Council. There was discussion that creating a uniform list of materials distributed to SIDS families throughout the state is important. With the rapid turnover in SIDS coordinators, such a list and availability as PDF documents would be extremely helpful.
- **Referral of Infants Dying Suddenly From Coroners to Public Health Nursing.**

Referral of SIDS, SUID, SUDI, and Undetermined families to Public Health.

Dennis Watt and *Tom Keens* spoke to the California State Coroners' Association on September 23, 2015, about the importance of referring the "families of any baby who died suddenly and unexpectedly, presumably during sleep, in whom the cause of death was not immediately apparent, including but not limited to SIDS, SUID, SUDI, Undetermined, and accidental deaths" to public health nursing so these families could receive help. Participants in the Council meeting were asked to give us feedback on how this is going. Most SIDS Coordinators on the call said that they were getting referrals. *Danielle Sees* mentioned a 1-day old baby who died in a hospital for whom she did not get the referral. As to sudden deaths in the first two weeks of life, *Doctor James Ribe* said that usually these deaths are not sleep-related and are in neonates that are symptomatic or suspected to have died from an identified medical problem. For that reason, they don't "look like" SIDS and may not get reported, because the Medical Examiner doesn't consider SIDS in his differential diagnosis due to the atypical presentation. He will work internally in the Los Angeles County Office of Coroner to create a mechanism so that these atypical deaths will also get reported. However, in general, the best way to insure receiving referrals is if SIDS coordinators contact the local coroners' offices and find a person willing to help assure that you receive referrals. We will keep track of this issue over time.



Revise Death Scene and Autopsy Protocols.

In general, there appears to be a clear consensus among California Coroners that the current *Death Scene Investigation* form is problematic, and that it should be revised. A subgroup of the CSCA, called the *Coroner's Curriculum Development Committee (CCDC)*, which meets on a regular basis, usually in Orange County, has agreed to conduct this review. This group is reasonably representative of "in the trenches coroner investigators", and they could serve as the core group. An initial meeting to discuss this issue was held on March 31, 2016, in Orange County. The next meeting will be on June 24, 2016, in Indian Wells.

There seems to be less interest in revising the Autopsy protocol. However, *Doctor James Ribe* indicated that the toxicology portion of the protocol was out of date, and this may also be an opportune time to review the autopsy protocol. He was asked to investigate among California medical examiners to see if there was a desire to change this and report back to the Council. He said, "As far as forming a statewide committee of pathologists to work on revising the state SIDS autopsy protocol, I will help out."

Data Analysis from Death Scene Investigation and Autopsy Protocols.

When *Dennis Watt* and *Tom Keens* spoke at the California State Coroners' Association meeting on September 23, 2016, and again on the telephone conference call on January 8, 2016, there was a loud and unified cry that they have been providing data to the State, but they do not see any results. That is, there are no data or information coming back to them based on the protocols they submit. *Carrie Florez* has previously told the Council that only 8% of protocols are completed, and that one can not derive meaningful data from such a small number. There seems to be agreement on that. However, if we successfully appeal to the Coroners to complete protocols and submit the data to the State, they need to be assured that they will receive some data in real time. *Tom Keens* had a discussion with *Addie Aguirre*, MCAH Brand of CDPH, on April 27, 2016. She indicated that she would attempt the speed up the time required for review of data before they are released.

SIDS Summit 2.

The *California State Coroners' Association* is 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. The conference will be 1½-day conference as part of the Annual Meeting of the *California State Coroner Association* in Palm Desert on September 22-23, 2016. Plans include an in depth review of a baby who died suddenly and unexpectedly, with all persons (or others who perform similar roles) involved in the case presenting their role. The purpose of the conference is not to second guess what was done right or wrong in the case presented. Rather, it is hoped that this case will be illustrative of everyone's role who touches a SIDS infant, from 911 call to family support. The second half-day will focus on all attendees struggling with the diagnosis and manner of death for a number of cases. Please see the *Save the Date* flyer at the end of these Minutes.

• Child Care Issues.

Lucy Chaidez explained that health and safety training, including SIDS/Safe Sleep training, for child care providers is limited to only one provider per home or center. Therefore, there are many child care providers in California who have never had the SIDS/Safe Sleep training, yet

they are taking care of babies. The best fix for this is to amend the child care provider training statute to require more hours of training more often and extend the training requirement to all child care provider staff. AB 1207, which was passed last year, will require SIDS/Safe Sleep training for all child care providers and all child care staff beginning January, 2018. However, the training module may be quite time-limited, as there are many other topics to cover in the on-line training. Once the AB 1207 module is developed, it will be important to know what is covered in the training regarding SIDS/Safe Sleep, and what isn't covered, as this will help to inform EMSA of what topics may still need to be covered in the in-person training. *Kyle Lafferty* of CDSS is in charge of the AB 1207 training project.

Lucy shared that CDSS is in the process of developing safe sleep regulations for licensed child care. The process will add safe sleep requirements to, and remove unsafe sleep regulations from, the current child care licensing laws. The regulations process was spurred by the Child Care Regulatory Workgroup *White Paper on Safe Sleep* that was submitted to CDSS in September 2012. Alison Myers of CDSS is in charge of this project.

Lucy explained the training that the child care LPAs (Licensed Program Analysts) must take. Below, is an excerpt from the current Federal Child Care Development Block Grant (CCDBG) California State Child Care Plan written and submitted to the Federal Government by the California Department of Education (CDE), in partnership with the California Department of Social Services (CDSS). [The CCDBG plan is required to be submitted every two years. CDE is considered the lead agency for the plan, but CDE receives much input from CDSS. The reason for this is that in California, we have a bifurcated system of child care oversight, with both the CDE and CDSS overseeing various aspects of child care. CDE oversees Head Start and some on-school-site preschools. And both agencies provide subsidized payments to child care providers to cover the care of children whose families meet the subsidy requirements. The Head Start system of child care is a model for well-trained child care staff, as it requires extensive and ongoing training for its trainers and teachers (aka child care providers).]

“The CDSS is mandated to make efforts to recruit Licensing Program Analysts (LPAs) with child care experience, training and education. The LPAs begin their training with a four-week long academy of coursework that includes: health and safety requirements and language and cultural diversity of the providers. In addition, LPAs are required to take 40 hours of Early Childhood Education training which addresses the developmental needs of children in care and type of provider setting. Lastly, the LPAs are required to complete 36 hours of training each year that includes regulation administration as well as communication, writing and human relations skills.”

Lucy also shared that the Child Care Resource and Referral Agency (R&R) is developing training for those people who are considered “license-exempt” child care providers. These are neighbors, friends, and family who provide care to children, but do so without having to be licensed by the Department of Social Services, and therefore do not have to follow child care health and safety regulations. The R&R has just completed its SIDS module. Tracy Tompkins of the R&R is in charge of this project.

Regarding the SIDS parent panel at the next 35th *Annual California SIDS Conference*, Lucy asked if the panel could be videotaped for use in child care provider training. The parent panels are so impactful and provide a strong message that may encourage child care providers to follow through with safe sleep guidelines.

As to training of child care providers, *Doctor James Ribe* noted that SIDS deaths in licensed child care facilities have been rare in his experience, but when they do happen they're a big horrible ordeal for everyone involved. Very much worth preventing. He mentioned from the literature that sleeping in child care is often an infant's "first prone" sleep.

Lucy also asked for the PHNs and Dr. Keens to share the e-cigarette ties to unsafe infant sleep situations. Lucy is on the state E-cigarette task force, and would like to share this information with her colleagues. There is no information about e-cigarettes and SIDS risk. However, second hand e-cigarette exposure is potentially worse than tobacco smoke exposure because it is an aerosol and penetrates deeper into the lungs than particulate tobacco smoke. Doctor Keens also indicated that in the current review of the California Death Scene Investigation Protocol, he is requesting that questions about e-cigarette use be added so that we may begin to acquire some of these data.

- **Southern California Regional SIDS Council.**

Kitty Roche, R.N., P.H.N., B.S.N., M.S.W., President of the Southern California SIDS Council, reported on the activities of the Southern California Regional SIDS Council.

The Council last met on February 11, 2016.

The Fund Raising Luncheon at The White House Restaurant in Anaheim, on April 4, 2016, sponsored by the Guild for Infant Survival, Orange County, was a success. The keynote speaker, Debbie Gemmill, was both poignant and inspirational.

The Daley Golf Tournament, sponsored by the Guild for Infant Survival, San Diego County, was postponed due to poor registration and will be rescheduled when possible.

Several members of the Council participated in the post Council meeting teleconference with the Child Care Curriculum work group in order to suggest Safe to Sleep education for Licensed Child Care Providers.

Southern California PHNs reported consistent presentations on Safe to Sleep in a variety of settings.

All reported a consistent effort to establish communication with the Coroner's Office to facilitate referrals for infants who died in sudden unexplained death situations.

It has been the process for SIDS Coordinators to mail a packet of resources and bereavement literature specific to SIDS. Since the presumed cause of death is now less consistently SIDS, we are in great need for more generic bereavement literature that addresses an infant death so



**Southern California Regional SIDS Council.
February 11, 2016, Meeting**

that families that may eventually be called SUID and Undetermined receive appropriate resources.

Several Southern California PHNs have been invited to participate in SIDS Summit II first in the planning and at the Summit itself to make the case for the importance of referral to the SIDS Coordinators.

The article on the Best Practice of Home Visits, written by Penny Stastny, PHN, Tom Keens, MD, and Abbey Alkon, RN, PhD, was published and utilized by the California SIDS Program in their state trainings as resource ².

The remaining Council meetings scheduled this year are on: 05/12/2016, 08/11/2016, and 11/10/2016 at the GISOC located at:

The Olive Crest Building
2130 East Fourth Street, Suite 125
Santa Ana, California 92705

The formal meetings are scheduled from 10 am-1 pm with the traditional 'after the meeting' meeting from 1:15 pm until ... at *Avila's El Ranchito Restaurant* located across the parking lot.

- **Northern California Regional SIDS Council.**

Natalie V. Berbick, M.S.W., President of the Northern California Regional SIDS Council, reported on activities of the Northern California Regional SIDS Council.

The council last met on April 22, 2016. As the hosts for the 35th Annual California SIDS Conference, the main objective of the meeting was to continue planning for the event. In collaboration with the California SIDS Program contractors and MCAH, the council voted to establish the dates, location, and venue for the conference, as the previous intended location was no longer an option due to scheduling limitations with the CDPH conference center in Richmond, California. The annual conference will be held on October 13th -14th, 2016 at the:



**Northern California Regional SIDS Council
February 19, 2016**

CDPH East End Complex
1500 Capitol Avenue
Sacramento, California 95814

² Stastny, P.F., T.G. Keens, and A. Alkon. Supporting SIDS families: the public health nurse SIDS home visit. *Public Health Nursing*, doi: 10.1111/phn.12251, 2016.

A “Save the Date” and preview agenda notification/flyer will be sent to the SIDS Community. This location was used in previous years, and was suitable for travel accommodations and the conference activities. A rich discussion ensued regarding the budget, theme, targeted audiences, suggested keynote speakers, integrating feedback from the 2015 annual conference, and consideration of allowing time for the California SIDS Awareness and Safe Sleep Education Day Activities. Further clarification about Boatwright Awardee recipients and keynote speaker eligibility/criteria was requested from MCAH/CDPH, as they have the final determination as to who is permitted to speak on the platform of the annual conference. The council members were reminded by the president that each presenter/speaker would be vetted, and that researchers would need to have valid and reputable credentials prior to presenting to the SIDS Community. Action items and deadlines were delegated to council members and California SIDS Program staff to support the progress in conference planning. An electronic survey was created and sent to the council membership, and responses will inform future conference planning.

In addition to conference planning, community reports from Alameda, Contra Costa, Solano, and San Francisco Counties were given, which indicated the interventions and strategies to bring awareness of SIDS/SUIDS and to promote safe sleep recommendations to various audiences, recent SIDS/SUIDS losses, local challenges and successes, and intra/interagency coordination with Coroners, other public health and ambulatory care providers, and efforts to engage the Child care provider communities in their respective local health jurisdiction was stated. Also, the council debriefed about the recent California SIDS Program Training for Emergency Personnel and Public Health Professionals, held on April 14, 2016, in San Jose. Many council members attended or participated in the planning of the training, and spoke favorably of the experience.

MCAH and California SIDS Program Contractors reported out regarding their activities, and solicited feedback from the council when appropriate.

Northern California Regional SIDS Council meetings will continue to be held at:

Contra Costa Crisis Center
307 Lennon Lane, Walnut Creek, California
9:30 AM -12:30 PM

The upcoming 2016 meeting dates are as follows: June 17th, Sept 9th, and Nov 18th.

- **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 remaining Council meetings in 2016, will be as follows:

- Tuesday, August 16, 2016; 1:30-3:30 p.m. via telephone Conference Call.
- In person meeting, Thursday, October 13, 2016, 1:00-4:00 p.m. in Sacramento, California. This will be the day before the 35th 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 3:19 P.M.

Respectfully submitted,

Lorie Gehrke
Vice Chair, 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**



**Natalie
Berbick**

Save the Date

SIDS Summit 2

At the California State
Coroner Association
Annual Meeting



September 22-23, 2016
Miramonte Resort and Spa

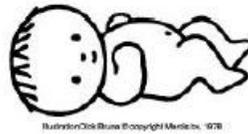
45000 Indian Wells Lane
Indian Wells, California 92210
Phone:(760) 341-2200



An Interdisciplinary 1½ day conference for Coroners, PHNs, first responders, CDRT, etc., to explore how determinations of the cause and manner of infant deaths are made, and to help understand the roles of everyone involved when a baby not breathing call comes in.

More Details to Follow

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



www.sap.org.ar

