



California Sudden Infant Death Syndrome Advisory Council

July 23, 2019 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.*
Heather Griffiths, *Coroner.*
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.*
Jeri Wilson, L.C.S.W., *President, Southern Calif. Regional SIDS Council.*
Lorie Gehrke, *Interim President, Northern Calif. Regional SIDS Council.*

Council Chair:

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Guests: Susana Aceves, R.N., P.H.N., B.S.N.; Steve Barrow; Gail Brodie; Robin Bunch, R.N., P.H.N.; ; Lucy Chaidez; Lynn Chamberlin, R.N.; Stella Cingmon, M.P.H.; Maria P. Cortez R.N., P.H.N. III; Sally Eberhard, P.H.N.II; Nicole Evans, M.S.W., M.B.A.; Alex Farrell (Michaud); Kitty Lee Gay, R.N.; Michelle Herrera; Veronica Martinez, P.H.N.; Shelley Parker, M.S.N.; Marcia Salomon, R.N., M.S.W.,



California Sudden Infant Death Syndrome Advisory Council



The Mission of the California SIDS Advisory Council is to advise the California Department of Public Health and energize Californians to:

- Alleviate the impact of SIDS, SUID, and other sleep related infant deaths on families by enhanced grief support from public health professionals and SIDS parent peer support.
- Reduce the number of SIDS, SUID, and other sleep related infant deaths by promoting safe infant sleep education by public health agencies and health care professionals.
- Reduce the racial-ethnic disparity in SIDS, SUID, and other sleep related infant death rates by developing innovative education strategies to address communities with increased infant death rates.
- Enhance public education about SIDS, SUID, and other sleep related infant deaths .
- Support research to identify the cause of and decrease SIDS, SUID, and other sleep related infant deaths.

"SIDS" includes all babies who die suddenly and unexpectedly without an identified cause, including SIDS, SUID, SUDI, Undetermined, ASSB, etc. diagnoses.

Members Present: Kathleen Beichley; Kris Concepcion; Dawn E. Dailey, Ph.D., R.N., P.H.C.N.S.-B.C.; Lorie Gehrke, N.C., Vice-Chair; Heather Griffiths; Thomas G. Keens, M.D., Chair; James K. Ribe, M.D., J.D.; and Kitty Roche, R.N., P.H.N, B.S.N., M.S.W.

Members Absent: Jeri Wilson, L.C.S.W.

State and California SIDS Program:

Candace Anderson, C.G.M.P.; Carrie J. Florez; Leslie Kowalewski; and Mari Taylan-Arcoleo.

M.P.H.; Michelle Scott B.S.N., R.N., P.H.N.; Theresa Somerville R.N.-P.H.; Sylvia Stratford, P.H.N.II; Brooke Treanor, R.N.; Laura Turner; Brandy Valentine; and Charlene E. Weiss-Wenzl, B.S.N., R.N., Sr.P.H.N., C.L.C.

The meeting was held by telephone conference call. All Council members were present; one ex-officio member was absent. The meeting was called to order at 1:31 PM., on July 23, 2019.¹

A Roster of California SIDS Advisory Council members is appended to these Minutes.

Introductions

Council members, state staff, and guests introduced themselves. California's *Bagley-Keene Open Meeting Act 2004* mandates that people may participate in the conference without identifying themselves in the Minutes.

Problems with Email Notifications from tkeens@gmail.com.

Tom Keens frequently sends emails to the California SIDS Community on a variety of topics, including information about California SIDS Advisory Council meetings and minutes, information on new research studies, requests for action, etc. Recently, many (most) of these emails are being blocked by the recipients. I know that many email servers have changed their firewalls. If you have not received emails from me in the past month, you may be blocking my emails. Please add me as a contact (tkeens@gmail.com), which may prevent my emails from being blocked. Also, check your Spam or Junk email folders for emails from me.

¹ Many terms are used to describe babies who die suddenly and unexpectedly during sleep in whom the cause cannot 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 these babies. These terms all mean the same thing when used to diagnose an individual infant: the death was unexpected and unexplained. In epidemiological studies, the term "SUID" is often an inclusive term which includes SIDS, Undetermined, and Asphyxiation Suffocation, and Strangulation in Bed (ASSB).

SIDS Parent Member of the California SIDS Advisory Council



Rachel Strickland, a SIDS parent and 2015 Senator Daniel E. Boatwright Awardee, has been one of three SIDS Parent members of the California SIDS Advisory Council since 2013. *Rachel* has been extremely active in the Southern California SIDS Community for many years. She was past President of the Southern California Regional SIDS Council, the Orange County Guild for Infant Survival, and the SIDS parent support group in Riverside County. She was in charge of an Annual California SIDS Conference. She has spoken on SIDS parent panels at California State SIDS Conference, SIDS trainings, and educational sessions to physicians and health care professionals. She is a bundle of energy and creative ideas to address SIDS issues in California. *Rachel* has moved to Las Vegas, and therefore she submitted her resignation as a SIDS Parent member of the California SIDS Advisory Council. We will miss *Rachel's* energy, enthusiasm, and productivity in California, but we wish her the very best of good fortune in her new life in Nevada.

To fill *Rachel's* SIDS Parent member vacancy. On June 2, 2019, *Tom Keens* sent an email to the California SIDS Community, inviting SIDS parents in California to apply for the position. Applications were due by July 5, 2019, allowing members of the community one-month to respond. Please note, "SIDS parent" members of the Council may also be those whose baby was diagnosed as SIDS, SUIID, SUDI, undetermined, or any other cause of death, which means that the death was unexpected and unexplained. Therefore, parents of babies who died with these causes of death are eligible to apply for this position. We received three applications, which were forwarded to the California Department of Public Health. They will be interviewing these applicants by telephone before forwarding their recommendation to the Director.

By California law, the California SIDS Advisory Council is composed of nine members, three of whom must be SIDS parents. Members of the California SIDS Advisory

Council are appointed by the Director of the California Department of Public Health, not by existing members of the Council.

California Department of Public Health/Maternal, Child, and Adolescent Health Branch.



**Mari
Taylan-Arcoleo**

**Carrie
Florez**

Carrie Florez, Mari Taylan-Arcoleo, and Leslie Kowalewski reported on the SIDS activities of the Maternal, Child, and Adolescent Health (MCAH) Branch of the California Department of Public Health (CDPH).

General:

- Starting to plan and elicit speakers for upcoming the SIDS/PHP Coordinator Meeting – Suggested presentations:
 - Establishing a relationship with Coroner’s Office – Work with Coroner SIDS Council Member
 - Conducting the Home Visit – Identify a speaker who can present information
 - Safe Sleep Interventions and Best Practices (Group Sharing) – highlight programs
- State MCAH is working closely to ensure the SIDS Contract will be in place soon. Much of the planning and securing of the site and speakers for the 2019 Annual SUID/SIDS Conference and the SIDS/PHP Coordinator Meeting have been secured through the previous contract.
- State MCAH is currently preparing the Safe Sleep Strategies for review/approval. It is anticipated to release the document in October 2019.

Five-Year Plan for the California SIDS Advisory Council in Addressing SUID/SIDS Issues in California

- State MCAH is currently underway in conducting the 5-year needs assessment (NA) for Title V funding.

- The NA will help identify the focus or priorities for the next five years for both State and Local efforts. The current priority for the State on infant health is the decrease in infant mortality rates.
 - Our SIDS Program aligns and contributes to the decrease in infant mortality rates and therefore receives Title V funding.
 - The SIDS Program not only provides grief and bereavement support services to families who have lost a baby suddenly and expectedly, but the SIDS Program also focuses on efforts and interventions to help reduce the risk of infants who die suddenly and unexpectedly.
- Funding for SIDS activities has decreased throughout the years, and current efforts are in place to support training and conference activities via our CSUS Partner. As State MCAH enters a new funding year plan, this is a great opportunity for the California SIDS Advisory Council to assist in maximizing SUID/SIDS efforts.
- State MCAH and Dr. Keens met face to face in June. Priority areas were identified and the active participation of the SIDS Advisory Council will be needed to support the priority areas and be part of the solution. State MCAH is looking forward to being better partners with the SIDS Advisory Council and accomplishing much-needed work.

Five-Year Plan for the California SIDS Advisory Council in Addressing SIDS Issues in California.

The five-year cycle for Title V funding of the California Department of Public Health is up, and a new cycle begins. The Maternal Child and Adolescent Branch of CDPH is actively planning what needs to be accomplished in California in each public health area, including the SIDS Program. I met with MCVAH/CDPH leadership, *Leslie Kowalewski, Mari Taylan, and Carrie Florez* in Los Angeles for ~2½ hours on June 13, 2019. We met to discuss the needs and actions we want to address in this next 5-year cycle. I was challenged with the question, “What is the role of the California SIDS Advisory Council with respect to solving the problems related to SIDS in California?” I immediately responded, “The California SIDS Advisory Council advises the California Department of Public Health on SIDS issues”. The question took me aback, as I realized that our Council could be doing much more. Certainly, there are problems with respect to SIDS in California yet to solve. So, I propose that the Council energize and rededicate itself to improving the state of SIDS in California.

Mission Statement:

As Yogi Berra said, “If you don’t know where you are going, you may not get there.” Our Council has not had a guiding vision, so it is not surprising that we have not had sustained efforts to advance SIDS services, education, and research in California. Many organizations have a Mission Statement to focus members and give direction

to action. Therefore, I proposed a Mission Statement for the California SIDS Advisory Council: *Doctor Ribe* commented that he felt the order of priorities in the proposed mission statement is appropriate. There was discussion over the first bullet point. *Doctor Ribe* supported the broad language of “reduce the impact”. Because in minority families, the impact is more than just “grief”. It includes social isolation, alienation, and family breakup. The Council decided on the word alleviate, which means to reduce or lighten, not to eliminate. The goal of SIDS parent support is to lessen the impact of a SIDS death, but as was pointed out, one cannot eliminate the impact. There was discussion about this, and modifications were made. A motion was made and seconded by Council members to approve this Mission Statement for the Council. The Council approved the motion unanimously.

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An extensive discussion occurred about the needs of the SIDS community in California and potential actions the Council could take.

Support for SIDS Families.

In California, grief support and SIDS education come primarily from two areas: public health professionals making home visits to families experiencing a SIDS death, and SIDS parent peer support.

Public Health Personnel:

Public health nurses are required by California law to make a home visit to families experiencing a SIDS death. However, making these visits can be scary for those nurses who have not made many visits, who do not know how to do it, and who are not trained. The MCAH/CDPH does not have data on how many SIDS Home Visits are actually made. There are many reports of PHNs trying to contact a family a few

times, and perhaps feeling some relief when they could not. We believe that new PHNs need to be educated how to make these visits. There is a rapid turnover of SIDS Coordinators, so that having access to an on-line tutorial whenever they get the job may be useful. We propose exploring innovative educational ideas to provide “SIDS Home Visit 101” training primarily for new PHNs.

One attendee suggested that the Safe Infant Sleep Curriculum for Nurses by the NICHD was a resource she used when she became a SIDS Coordinator. Although this curriculum includes information about SIDS, SUID, and other sleep-related infant deaths, it is more focused on promoting safe infant sleep than supporting SIDS families. The curriculum can be accessed at: [Risk Reduction for SIDS and Other Sleep-Related Causes of Infant Death: Continuing Education Activity for Nurses](#)

Newer PHNs, especially those assuming the role of a County SIDS Coordinator, need support. Historically, the SIDS Program has provided the names of experienced SIDS Coordinators to serve as a mentor to new SIDS Coordinators. Thought this practice is in place, it does not seem that it is well advertised, as some new SIDS Coordinators on the call were unaware that mentors were available. We need to make this resource more visible. New SIDS Coordinators should be given the names of their potential mentors, and mentors also expressed a desire to be given the names of new SIDS Coordinators so that they can reach out to them. Currently, experienced SIDS coordinators serving as mentors are Claudia Benton, Deja Castro, Dawn Daily, Kitty Roche, and Michelle Scott. This program should be continued and promoted.

New SIDS Coordinators, and interested public health nurses may benefit from practice on making a home visit. We discussed the possibility at the SIDS Coordinator meeting preceding the 2019 California SIDS Conference to have small groups composed of an experienced PHN/SIDS Coordinator with newer SIDS Coordinators to role-play specific scenarios. This would be in addition to a virtual or on-line educational module, not instead of it. This was suggested to the MCAH, who is planning the SIDS Coordinator meeting on October 16, 2019, before the 38th Annual California SIDS Conference.

The California SIDS Program initiated the development of a Handbook for PHNs on how to make a SIDS home visit. Some work has been done on this. It is not clear where this stands. *Carrie Florez* said that some preliminary material has been turned in to the MCAH.CDPH branch. She said the information appeared incomplete. She will share this initially with *Tom Keens*, and they may make modifications, and then share this with a group of experienced SIDS Coordinators to try and move this along. This is a resource which could be potentially valuable to new SIDS Coordinators.

Education for PHNs to make home visits to families experiencing a SIDS death should be improved so that every PHN assigned to this task feels comfortable doing so, and realizes the importance to what they are doing. As one measure of progress, I suggest that MCAH/CDPH collect data on how many SIDS families receive home visits.

Doctor Ribe commented that the Coroner's investigator is the first responder to every SIDS death because she has to recover the body and talk to the family about what happened. These investigators are extremely valuable to families in numerous aspects of the early phase of SIDS. They are a tremendous resource if properly utilized. *Tom Keens* asked what training they receive. *Heather Griffiths*, Coroner Member of the Council, said that training is needed for Coroner-investigators, as they receive very little. The issue of some Coroners still not referring families to public health nursing for grief support and education was also brought up. *Tom Keens* suggested that *Heather Griffiths* work with the California State Coroner's Association to see if we could get such training on the Agenda for their annual meeting, which is usually in September. It is probably too late for the 2019 meeting, but perhaps we could have an educational session at their 2020 annual meeting. *Tom Keens* and *Dennis Watt* (previous Coroner investigator member of the Council) did a number of similar educational sessions at this meeting over the years.

SIDS Parent Peer Support:

Nearly all SIDS parents will tell you that the greatest source of support for them is speaking with another parent who has also had a baby die from SIDS. SIDS Parent Support groups once flourished in many parts of California, yet few remain. Southern California has only two active groups, and Northern California has none. Some SIDS parents still provide one-on-one support for newly bereaved families, but these are few in number and hard to find. Many SIDS parents receive support online, which is better than nothing, but it may not be as good as in-person support. A number of SIDS parents at the meeting relayed how helpful in person SIDS parent support was for them. However, many stated that after some time has passed since their baby's death, many parents do not find SIDS parent support meetings as helpful. The experience with Northern California and at least one group in Southern California is that parents stopped coming to meetings, so the groups discontinued.

What is the best form of support for SIDS families? Should we try to promote traditional in-person SIDS parent support groups in California? If so, how do we do that? The geographical distance was brought up as an obstacle. Many would have to travel great distances to attend an in-person meeting. Many SIDS parents provide one-on-one support for newly bereaved families, by telephone and/or in person. This is effective. Online support seems increasingly popular. *Tom Keens* asked attendees to think about what is most needed in California to promote SIDS Parent peer support.

SIDS parents who do provide peer support are not trained in some of the problems that can arise when counseling others. Are they trained to handle suicidal ideations or threats of harm to self or others, for example? Several years ago, the California SIDS Program offered SIDS peer training a few times per year. We would like to propose that we develop a SIDS Parent Peer Training program, and offer it to any SIDS parent interested in becoming a SIDS Peer Contact. This will give us better trained SIDS Peer Contacts, and maybe increase the numbers we have available. The California

SIDS Program looked into existing on-line training programs, but they did not seem to meet our needs. Then, they started to develop such a program. Where does that stand? I suggest that we collect what has been done and finish the task of creating a program. This should be reviewed by those in the California SIDS community who are appropriate and by the California SIDS Advisory Council.

Safe Infant Sleep Education.

The “Back to Sleep” then “Safe to Sleep” campaign has resulted in a dramatic decrease in SIDS death since 1990. However, the SIDS rate has remained stable since 2000. The SIDS rate remains highest among indigenous people (native American Indians and Eskimos) and African-Americans, despite decreases in other racial-ethnic categories. Studies show that many parents do not adhere to Safe to Sleep recommendations, even if they have been educated about them. Health care professionals do not consistently provide Safe Sleep education to families.

The Safe Sleep Education we are providing is not working adequately. Specifically, we are not reaching the highest risk populations --- indigenous populations and the African-American community. I believe that we can do a better job. There are racial-ethnic, cultural influences that affect health behavior which I am not sure we understand. We would like to suggest that we convene a group of health educators, individuals from the high-risk groups, and others to rethink Safe Sleep Education from the beginning. What is needed to achieve success across all racial-ethnic groups? What are we not doing to meet these needs? What can we change to improve outcomes? What do we need to do to close the disparity in SIDS rates? We would like to propose that we convene a working group of experts to focus on how to do a better job with Safe to Sleep education. As opposed to our traditional format, we would like to convene a working group of health educators, SIDS experts, and others to brainstorm about new ways to do Safe Sleep Education that will impact all groups.

Studies show that many health care professionals are complacent about teaching safe infant sleep. How can we motivate a multi-tiered education for families from prenatal through infancy by pediatricians, hospitals, obstetricians, and public health agencies? Is SIDS being taught in health professional schools? Can we influence the deans of the California Medical Schools to include at least some education about SIDS in a four-year M.D. curriculum? Can we influence the deans of California nursing schools to include SIDS and safe infant sleep education in their nursing school curricula?

Safe infant sleep education can be improved by thinking of new ways to close disparities in SIDS rates by using targeted approaches to the highest risk groups, motivating health care professionals from obstetricians and prenatal classes through pediatricians to provide this education, and to attempt to infuse medical and nursing school curricula to include SIDS information.

Tom asked how we can better reach minority communities with safe sleep education. *Doctor Ribe* replied that the State should address the question, “Who’s we?” *Dr. Ribe*

also said that “the Advisory Council and the whole effort should become black, brown, and red.”

California Unintentional Injury Prevention Strategic Plan Project:

Steve Barrow, Co-Chair, provided an update on activities and invited interested attendees to help in reducing the risk of infant deaths.

The California Coalition for Children’s Safety and Health (CCCSH) is a 26+-year-old statewide coalition focused on childhood unintentional injury prevention. CCCSH has a partnership with both the CA Dept of Public Health (CDPH) and CA Emergency Medical Services Administration (EMSA).

CCCSH staffs and hosts the statewide CA Unintentional Injury Prevention Strategic Plan Project (Project). The Project’s mission is to support efforts across the state to end unintentional injury as the leading cause of death and hospitalizations for California’s children and youth through age 19 years old. As you know best - SIDS and infant/baby sleep suffocation issues are leading causes of unintentional injury death and hospitalization for CA’s children under the age of 1 year old.

The Project is focused on the eight leading causes of unintentional injury for California’s children and youth including: traffic related (vehicle, bicycle and pedestrian), drowning (primarily both pool and open bodies of water), poisoning (primarily prescription meds, lead and household toxic substances), burns (primarily home fires and kitchen hazards), falls (primarily residential window falls), non-traffic vehicle related (primarily kids left in vehicles, driveway backovers), sports-related (primarily concussions, heatstroke, cardiac arrest and spinal injury), and suffocation (Project’s primary focus is on infant/baby sleep suffocation).

CCCSH is staffing and partnering with the CA DPH SACB the fall 2020 statewide childhood unintentional injury conference.

If you are interested in learning more about CCCSH, the Project or the fall 2020 Unintentional Injury Conference you can contact Catherine Barankin, Executive Director or Steve Barrow, Program Director CCCSH at cbarankin@gmail.com or sbarrow88@gmail.com.

Spring SIDS Trainings.

The Spring SIDS Trainings currently are filling to capacity, so they seem popular, and they are presumably filling a need. We note that the attendance is now more varied and does not consist of only PHN/SIDS Coordinators, but we are also getting social workers, childcare personnel, first responders, etc. It seems that the current model for Spring SIDS Trainings is meeting a need, and should probably continue along their current lines for the time being.

Senator Daniel E. Boatwright Award.

At its February 14, 2019, meeting, the *Southern California Regional SIDS Council* decided that voting for the recipient of the 2019 *Senator Daniel E. Boatwright Award* will be open to all members of the California SIDS Community who wish to vote. On June 1, 2019, *Tom Keens* sent an email to members of the California SIDS Community inviting them to nominate a person who exhibits “extraordinary public service on behalf of Californians touched by sudden infant death syndrome” to receive the 2019 Senator Daniel E. Boatwright Award. The Community had one-month to submit nominations (closed July 5, 2019). Previous *Senator Daniel E. Boatwright Awardees* are not eligible to receive the award more than once. We received only 10 votes. The Southern California Regional SIDS Council will review this information and decide how to proceed at its upcoming meeting on August 8, 2019.

Highlight Santa Clara County Safe Infant Sleep Program.

Lynn Chamberlin, R.N., SIDS Coordinator, Santa Clara Public Health Department, informed us about the Safe Infant Sleep Program she has started in Santa Clara County. “I am the SIDS Coordinator for Santa Clara County and I wanted to ask all the SIDS Coordinators what they are doing to spread the word of safe sleep in their County. In this County I have worked to confirm that the 10 birthing hospitals have safe sleep materials that they share with their moms at delivery and every October the safe sleep message is promoted on our Public Health Website and tabling is done at each of our 4 clinic sites. I have trained all of our Public Health Nurses on safe sleep and it is protocol that each nurse discusses the subject when doing home visits to prenatal and postnatal moms. A few years ago we teamed up with First Five and a Safe Sleep video was produced starring our Chief Medical Examiner and an actual parent whose child died from unsafe sleep practices. Signs were posted on the back of buses and in the malls promoting the message as well. I am looking to find out other ideas of how to spread the word that have been successful in your particular county.”

Periodically, I would like to highlight what California Counties are doing to improve SIDS services, education, and research in California.

Child Care Issues:

Laura Turner, Associate Governmental Program Analyst – Policy, Child Care Licensing Program, California Department of Social Services, presented the following update on Child Care issues:

1. Total sleep-related deaths and update on website information.
 - a. 9 sleep-related deaths as of July 2019

- b. CCLD will be moving toward posting child deaths on the CCLD website in order to comply with the Child Care Development Block Grant Posting Requirement.
2. How does SIDS or sleep-related deaths fit into the discussion around adverse childhood experiences?
 - a. If anyone has any experience or information they can provide regarding this topic, please email Community Care Licensing Child Care Policy Analyst Laura Turner at Laura.turner@dss.ca.gov.
3. Current response from a regional office to a facility where a death has occurred.
 - a. Licensing staff visits the facility to review the incident with the licensee and discussing safe sleep practices.
 - b. The staff provides information to the licensee on local SIDs Coordinators/Public Health Nurses for grief care.
 - c. If it has not already been done, the licensing regional office reaches out to school districts, Offices of Education, large providers, R&Rs, and conducts a county-specific outreach/training in partnership with local SIDS Coordinators & Public Health.
 - d. The office utilizes the Public Health Nurses for initial visits following a death.
 - e. There is a focus on the quality of the visit and improved communication with providers. The office performs a consultative role, disseminating safe sleep information.
4. Update on Safe Sleep regulations package.
 - a. Safe Sleep Regulation package was submitted to the Office of Administrative Law on 7/2/19. They have 30 business days to respond. As of today, we have not heard anything from them.
 - b. CDSS released two Provider Information Notices ([PIN 19-06-CCP](#) and [PIN 19-10-CCP](#)) informing licensees of the recent infant sleeper recalls.

2020 International Society for the Study and Prevention of Perinatal and Infant Deaths (ISPID) International Conference.

Stillbirth, neonatal death and sudden unexpected death in infancy: drivers for global change

The [International Stillbirth Alliance \(ISA\)](#) and the [International Society for the study and prevention of Perinatal and Infant Death \(ISPID\)](#), in conjunction with the Australian

Centre of Research Excellence in Stillbirth warmly invite you to the 2020 International Conference to address Stillbirth, Neonatal death and Sudden Unexpected Death in Infancy (SUDI) globally. We are very excited to be hosting this important event!

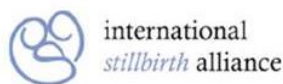
Dates: October 22nd-24th 2020

Venue: Convention and Exhibition Centre, Brisbane, Australia

Details: The major theme of the conference is *Drivers for Global Change*. Our aim is to showcase strategies to effectively address the burden of stillbirth, neonatal death and SUDI across high, middle and low-income country settings. The ISA/ISPID 2020 conference provides a unique opportunity for parents, parent advocates, health care professionals, researchers, professional colleges, and policymakers to come together, with the aim of reducing stillbirth, and infant death by improving care and outcomes for families who suffer this tragic loss.

22 - 24 October, 2020

Brisbane Convention Centre, Queensland, AUSTRALIA



California SIDS Program.



**Deborah
Hunt**



**Kay
Evans**



**Candace
Anderson**



Candace Anderson presented the activities of the *California SIDS Program*.

SIDS Spring Trainings

- Dr. Tom Keens – current research and Safe Infant Sleep
- Grief – Lorie Gehrke and Michelle Gentle
- Parent panel – Lorie Gehrke, Kris Concepcion, and Laurie Hollins, moderated by Susanna Flores. Michelle Herrera, Corey Gligo, April Myers, moderated by Penney Stastny
- Coroner Panel – Heather Griffiths
- CDPH – SUID, Process, Trends, Education
- Presentations are on the registration websites (google 2019 SUID/SIDS training)
April 26 in Fairfield, Solano County

106 attendees

Thanks to MCAH of Solano County, First 5 Solano, Kaiser Permanente, and Kris Concepcion, Fire Chief, City of Vacaville, Solano County. Solano County asked to host this meeting and found us a beautiful venue and Kris was instrumental in securing sponsorship from First 5 Solano and Kaiser to provide refreshments which made the meeting a very positive experience. Without their efforts, the meeting would not have been productive as it was.

June 12 in downtown Los Angeles

75 attendees

Thanks to Heather Griffiths for coordinating both northern and southern coroner panels, and to the Joan Palevsky Center for the Future of Los Angeles, and the California Community Foundation, who provide the space and audiovisual at no cost.

Annual Conference

October 17 at the Queen Mary in Long Beach

Confirmed talks

- Dr. Rachel Moon
- Keynote: Safe Sleep
- Professional Breakout: Safe Infant Sleep: Questions Parents Ask that You're Afraid to Answer
- Community Resiliency Model – Kelley Barragan, RN, PHN
- Parent breakout on grief – Kathleen Cromwell based on the previous presentation: "THE LIFELONG JOURNEY; FOREVER MY CHILD"

Pre-Conference Meeting Schedule

Pre-Conference Meetings – October 16, 2019	
8:30 am – 9:00 am	Registration for CDPH/PHN Meeting
9:00 am – 10:00 am	CDPH/PHN Meeting
10:00 – 10:15 am	Break
10:15 am – 11:45 am	CDPH/PHN Meeting
11:45 am – 1:15 pm	Lunch on own
1:15 pm – 2:45 pm	CDPH/PHN Meeting
2:45 pm – 3:00 pm	Break
3:00 pm – 5:00 pm	SIDS Advisory Council Meeting
5:30 pm – 7:30 pm	Welcome Reception – 38 th annual SIDS conference

	38th Annual California SIDS Conference
8:00-8:05 a.m.	Welcome Remarks
8:05-8:15 a.m.	Memorial Service (Christina will coordinate video)
8:15-9:45 a.m.	<p>Keynote Presentation - Safe Sleep: Why parents do what they do</p> <p><i>Rachel Y. Moon, M.D.</i></p> <p><i>Harrison Distinguished Teaching Professor of Pediatrics; Division Head, General Pediatrics; University of Virginia School of Medicine/</i></p> <p>Presentation of the medical/scientific factors influencing unexpected infant deaths; the definitions of different diagnoses; the interplay between genetics/vulnerability and environment/lifestyle/behavior; brain dysfunction and arousal; risk factors; social norms; and research on decision making and changing behavior through social marketing.</p>
9:45-9:55 a.m.	Senator Daniel E. Boatwright Award
9:55-10:10 a.m.	Break
10:10-11:45 a.m.	<p>Parent's Breakout – Kathy Cromwell (grief presentation tailored to parents who have experienced loss).</p> <p>Professional Breakout - Safe Infant Sleep: Questions Parents Ask that You're Afraid to Answer</p> <p><i>Rachel Y. Moon, M.D.</i></p> <p><i>Harrison Distinguished Teaching Professor of Pediatrics; Division Head, General Pediatrics; University of Virginia School of Medicine</i></p> <p>Interactive session in which we break into groups, and assign each group a commonly encountered scenario. The groups discuss how they would handle their scenarios, and then each group presents what they would do. All participants then would discuss.</p>
11:45-1:15 p.m.	Lunch
1:15-2:15 p.m.	SIDS Parent Panel
2:15-2:30 p.m.	Break

2:30-3:45 p.m.	<p>The Community Resiliency Model®</p> <p><i>Kelley Barragan, RN, PHN, MS, SIDS Coordinator, Santa Barbara County Public Health Department</i></p> <p><i>Florene Bednersh, PhD., Executive Director, Children and Family Resources.</i></p> <p>An overview of the Community Resiliency Model (CRM), which teaches a set of skills that help us to be our best selves when facing the world. It allows us to stay or get back to our resilient zone which is where we have the ability to face stressors head on. There is a connection between the mind and body and it is important for us to recognize the sensations of distress vs. wellbeing. This session will present exercises to practice the three core skills of Tracking, Resourcing, and Grounding.</p>
3:45-4:00 p.m.	Quotes of hope and resiliency from parents (Rachel Strickland)

Provisional Schedule and Agenda are below:

Peer Mentoring/Support for new coordinators:

Sac State works with CDPH to provide mentor list and inform mentors when a new coordinator is brought on board.

Southern California Regional SIDS Council



Jeri Wilson, L.C.S.W., President of the Southern California Regional SIDS Council, submitted the written report on the Southern California Regional SIDS Council, but she was not able to attend the meeting to present it.

The Council last met on May 2, 2019.

- We discussed the SIDS International conference that will be held on October 22-24th in Brisbane, Australia. It would be great if we could have someone from California at the conference representing us.
- We continue to work towards making this years' conference a fabulous one. Our conference chair Michelle Herrera has been leading the charge and has confirmed that our Key Note Speaker and break-out session facilitator will be Dr. Rachel Moon.
- We are in need of pictures and quotes for the babies that will be remembered at the conference. Please email Rachel Strickland or Lindsay Wilson at lindsayw5678@gmail.com with –'Conference Pictures' in the subject line.
- We are coming up with ideas for how each county will promote safe sleep and SIDS awareness for the month of October.
- And because Tom got so few votes for the Boatwright Award we will be voting on the recipient at our next meeting on August 8th.

- Thank you to those of you that have donated to fund the Welcome Reception.

We are in need of:

- Another good fundraiser....
- Conference Attendees-please pass along the conference registration form to any MD's, NP's, Social Workers, Therapists, Child Welfare Personnel and Child Care Workers or anyone that you think would benefit from the conference. If each of us made a commitment to invite 5 new people we would be educating and changing even more lives!

The *Southern California Regional SIDS Council* holds four meetings per year. The remaining meetings for 2019 will be held at the Department of Health and Human Services, City of Long Beach, 2525 Grand Avenue, Long Beach, California 90815. on the following dates:

- August 8, 2019, at 10:00 a.m.- 1:00 p.m.
- November 14, 2019, at 10:00 a.m.- 1:00 p.m.

Northern California Regional SIDS Council

Lorie Gehrke, Interim President of the Northern California Regional SIDS Council, reported on activities of the Northern California Regional SIDS Council.



The Council last met on July 17, 2019

- We discussed preliminary plans for the 2020 conference and ideas for Spring 2020 training.
 - We received very positive feedback on the Spring 2019 training in Solano County, including the comment that it should be a model for future events - the locale was very nice, plenty of space, nice amenities, and food. Kudos to Kris Concepcion and Mariejoy Supapo for making it happen, including

procuring subsidies from First Five Solano and Kaiser Permanente to provide breakfast and lunch.

- Some of the more pressing issues we discussed have already been addressed during today's Council meeting, including coroner communication issues and risk reduction education.
 - At least two Northern California counties are experiencing increased difficulty in communications with coroner – no written notes, little to no reporting, and very reduced communication – all making it difficult for PHNs to do their jobs. We discussed how this might be due to an interpretation of legislation regarding how the coroner can communicate information, but note this is not happening in all counties.
 - We also discussed continuing concerns about risk reduction education, including at least one county considering educating on “safer” co-sleeping.
- San Joaquin County (*Michelle Scott*) has been awarded a SafeKIDS grant for 200 Pak n Plays and Fresno and Madera County are working on similar Pak N Play programs. We talked in some detail about the CRIBS for KIDS program and how it can be implemented.
- *Sylvia Stratford* from Madera County recommended “Bearing the Unbearable, a book on love and loss by Joanne Cacciatori.
- We discussed positive new partnerships happening in many counties with childcare licensing (including trainings). *Brandy Valentine* commented to keep in mind the need for protocols on how to talk to parents too.
- Nominations are open through August 30, 2019 for President, Vice President, and Secretary of the Northern California Regional Council. We will vote at our next meeting for a January 1st effective date. We discussed sending a description of the offices and details regarding the commitment to all Northern California members.

2019 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 following meeting of the Council for the remainder of 2019 is

- In-person meeting will be the day before the *38th Annual California SIDS Conference* on Wednesday, October 16, 2019, 3:00-5:00 p.m., at the Queen Mary Hotel in Long Beach, California. determined.

The *California SIDS Advisory Council* set the calendar of meetings for 2020, as follows:

- Tuesday, January 21, 2020; 1:30-3:30 p.m. via telephone Conference Call.
- Tuesday, April 21, 2020; 1:30-3:30 p.m. via telephone Conference Call.
- Tuesday, July 21, 2020; 1:30-3:30 p.m. via telephone Conference Call.

- In-person meeting will be the day before the *39th Annual California SIDS Conference*, date and location are yet to be determined.

By California's *Bagley-Keene Open Meeting Law 2004*, 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 3:28 p.m.

Respectfully submitted,

Lorie Gehrke
Vice Chair, California SIDS Advisory Council

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





Registration will open soon for the
38th Annual California SIDS/SUID Conference
to be held October 17, 2019,
on the historic ship Queen Mary in Long Beach, CA.

Our theme this year is *"Honoring Our Past . . . Embracing Our Future"*. We hope you will join us as we share, learn, and gain perspectives on sudden infant death.

Tentative Schedule (subject to change)

Pre-Conference Meetings: Wednesday, October 16, 2019

8:30 a.m. CDPH/PHN Meeting

3:00 p.m. California SIDS Advisory Council Meeting

5:30 p.m. Parents' Reception

38th Annual Conference: Thursday, October 17, 2019

7:00 a.m. Conference Check In

8:00 a.m. Welcome Address

8:05 a.m. Memorial
8:15 a.m. Keynote Speaker - Dr. Rachel Moon
9:45 a.m. Senator Daniel E. Boatwright Award
9:55 a.m. Break
10:10 a.m. Breakout Sessions
11:45 p.m. Lunch on Your Own
1:15 p.m. Parent Panel
2:15 p.m. Break
2:30 p.m. The Community Resiliency Model
3:45 p.m. Closing Comments

Who Should Attend?

Parents, families, caregivers, public health professionals/administrators, SIDS Coordinators/Public Health Professionals, social workers, nurses, physicians, coroners/medical examiners, investigators, and emergency first responders touched by unknown/undetermined, sudden unexpected/unexplained infant death (SUID), SIDS, positional asphyxia/asphyxia, and accidental suffocation and strangulation in bed.

Registration information will be arriving soon, but **reservations are now open at the hotel:**

The Queen Mary

1126 Queens Hwy

Long Beach, CA 90802

Phone: 1-800-808-5253

We have reserved a small block of rooms at the state rate of \$120 plus tax for the nights of October 15 & 16. The hotel has agreed to waive the usual

facility fee for our group. Reservations must be booked before September 16.

To reserve your stateroom on board this historic ship, **please call the hotel's reservations department at (877) 342-0742 and reference the "2019 SIDS Conference Group"** to receive our group rate.

Sincerely,
California SIDS Program
California State University, Sacramento

California Sudden Infant Death Syndrome/Sudden Unexpected Infant Death (SIDS/SUID)

Program Mentors

The following is a list of SIDS Coordinators/Public Health Professionals throughout the State who have years of experience and expertise serving families who have experienced a sudden unexpected infant loss and promoting risk reduction at the local level. We encourage you to contact one of the mentors in your region for technical assistance and guidance as you assume the responsibilities of SIDS Coordinator/Public Health Professional for your health jurisdiction.

Name	Agency and Address	Phone
NORTHERN CALIFORNIA REGION		
Dawn Dailey, Rn, PHN, PhD	Contra Costa County Health Department E-Mail: Dawn.Dailey@hsd.cccounty.us	(923) 313-6325
Michelle Scott, PHN	San Joaquin County Public Health Nursing E-Mail: mScott@sjcphs.org	(209) 468-3050
CENTRAL CALIFORNIA REGION		
(VACANT)		
SOUTHERN CALIFORNIA REGION		
Deja Castro, PHN	Riverside University Health System Department of Public Health E-Mail: dcastro@rivcocha.org	(951) 210-1153
Claudia Pineda Benton, MSN, RN-BC, PHN	Ventura County Public Health Department E-Mail: Claudia.Benton@ventura.org	(805) 981-5380
Kathleen "Kitty" Roche, RN, PHN, BSN, MSW	San Diego County Health/Human Services Agency, Retired E-Mail: kitty065@gmail.com	(760) 390-4576 (cell)



July 30, 2019

Dear Community Member,

My name is Michelle Herrera, and I am with the [San Diego Guild for Infant Survival](#). As a SIDS parent, I provide peer support for parents and families who have experienced the sudden and unexpected death of an infant. I am also the Chair of the planning committee for the 38th Annual California SIDS/SUID Conference at the Queen Mary in Long Beach on October 16 & 17.

We are requesting donations so we can help our SIDS/SUID/Undetermined families with hotel accommodations and travel expenses. Our goal is to raise \$1000. A donation of \$25.00 will help relieve the financial hardship some of our families experience.

You can send contributions to the San Diego Guild for Infant Survival, which is a 501(c)(3) non-profit organization. To make a donation online please visit our website at [San Diego SIDS Donations](#).

The San Diego Guild for Infant Survival would like to thank you in advance for your support!

Sincerely,

Michelle Herrera
San Diego Guild for Infant Survival
P.O. Box 421515
San Diego, CA 92142-1515
Website: [San Diego SIDS](#)



California Sudden Infant Death Syndrome Advisory Council

ROSTER		
<p>SIDS PARENT Kathleen Beichley 1605 Highland Drive Placerville, CA 95667 Home: (530) 622-8474 Cell: (530) 748-7874 beichley@comcast.net</p>	<p>FIRST RESPONDER Kris Concepcion Fire Chief, City of Vacaville 650 Merchant Street Vacaville, CA 95688 Office: (707) 449-5462 Cell: (949) 426-2240 Kris.concepcion@cityofvacaville.com Kconcepcion24@gmail.com</p>	<p>PUBLIC HEALTH NURSE Dawn Dailey, RN, PHN, PhD MCAH Nurse Manager Contra Costa Health Services Nurse Family Partnership 597 Center Avenue, Suite 365 Martinez, CA 94553 Work: (925) 313-6325 Dawn.Dailey@hsd.cccounty.us</p>
<p>VICE CHAIR/SIDS PARENT Lorie Gehrke 1324 Bodega Place Walnut Creek, CA 94597 lorie@mariposaliving.com</p>	<p>CORONER Heather Griffiths Deputy Coroner Sacramento County Coroner's Office 4800 Broadway, Suite 100 Sacramento, CA 95820 Phone: (916) 874-1703 griffithsh@saccounty.net</p>	<p>CHAIR/PHYSICIAN Thomas G. Keens, MD Division of Pediatric Pulmonology Children's Hospital Los Angeles 1650 Sunset Blvd., Box #83 Los Angeles, CA 90027 Office: (323) 361-2101 tkeens@chla.usc.edu tkeens@gmail.com</p>
<p>MEDICAL EXAMINER James K. Ribe, MD, JD 18156 Kingsport Drive Malibu, CA 90165 Phone: (310) 459-4351 Atlantic2677@hotmail.com</p>	<p>PUBLIC HEALTH NURSE Kathleen (Kitty) Roche, PHN, BSN, MSW 3747 Vista Campana S #102 Oceanside, CA 92057 Cell: (860) 300-4576 Kitty065@gmail.com</p>	<p>SIDS PARENT VACANT</p>
<p>NORTHERN CALIFORNIA SIDS COUNCIL Lorie Gehrke, President 1324 Bodega Place Walnut Creek, CA 94597 Cell: (925) 207-8113 lorie@mariposaliving.com</p>	<p>SOUTHERN CALIFORNIA SIDS COUNCIL Jeri Wilson, LCSW, President PO Box 710733 Santee, CA 92072 Cell: (619) 888-0616 wilsonjeriellen@gmail.com</p>	

California SIDS Advisory Council



Kathleen Beichley



Kristian Concepcion



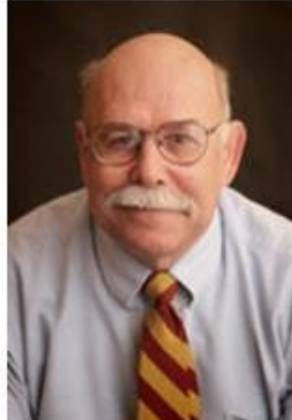
Dawn Dailey



Lorie Gehrke



Heather Griffiths



Tom Keens



James Ribe



Kitty Roche



Rachel Strickland



Jeri Wilson