California Sudden Infant Death Syndrome Advisory Council

October 16, 2019, Meeting

The Queen Mary Hotel
1126 Queens Highway
Long Beach, California 90802

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 (by telephone)**; Thomas G. Keens, M.D., **Chair**; James K. Ribe, M.D., J.D.; Kitty Roche, R.N., P.H.N, B.S.N., M.S.W.; and Jeri Wilson, L.C.S.W.
- **Members Absent:** Heather Griffiths
- **State and California SIDS Program:** Candance Anderson, C.G.M.P.; Carrie J. Florez; Deb Hunt; and Mari Taylan-Arcoleo
• **Guests**: Susana Aceves, R.N., P.H.N., B.S.N.; Natalie Adolph; Duane Beichley; Vella Black-Roberts; Christina Boothman; Deja Castro, R.N., P.H.N.; Stella Clingmon, M.P.H.; Peggy Concepcion; Maria P. Cortez R.N., P.H.N. III; Jacinda Croissant; Ann Dickman; Sally Eberhard, P.H.N.II; Susie Fanning; Kitty Lee Gay, R.N.; Jennifer Gross; Karen Gross; Michelle Herrera; Rowena Inocentu; Rebecca Melero; Czarina Marasigan; Patricia Molina, P.H.N.; Susan Philo, Sr.P.H.N.; Robin Qualls; Maureen Rubalcaba; Marcia Salomon, R.N., M.S.W., M.P.H.; Melanie Schimpf, R.N.; Michelle Scott B.S.N., R.N., P.H.N.; Danielle Sees, R.N., B.S.N., P.H.N., I.B.C.L.C.; Sylvia Stratford, P.H.N.II; Rachel Strickland; Ofelia Toledo-Prieto; Gabriela Trejo; Brandy Valentine; and Zoua Vang.

• The meeting was held in person at the Queen Mary Hotel in Long Beach, California. A majority of Council members were present. The meeting was called to order at 3:10 P.M., on October 16, 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.

• **2019 Senator Daniel E. Boatwright Awardees: Deja Castro and Kris Concepcion.**

  The California SIDS Advisory Council, and the California SIDS Community, congratulate Deja Castro, R.N., P.H.N., and Kris Concepcion as the 2019 recipients of the Senator Daniel E. Boatwright Award “for extraordinary public service on behalf of Californians touched by sudden infant death syndrome.” Tom Keens presented them with their awards at the 38th Annual California SIDS Conference on The Queen Mary on October 17, 2019. Deja Castro was honored as the SIDS Coordinator and PHN in Riverside County who provided support to SIDS families above and beyond the call of duty, and who has developed innovative strategies to promote safe infant sleep education. Kris Concepcion was honored as a SIDS parent and first responder who is promoting education to first responders on supporting SIDS families, conducting a compassionate investigation at the time of death, and safe infant sleep.

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 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).
Both Deja and Kris are richly deserving of this award, and we congratulate them and thank them for all they are doing for the California SIDS Community.

In keeping with the theme of the 38th Annual California SIDS Conference – “Honoring Our Past; Embracing Our Future” – the California SIDS community presented two “Lifetime Achievement Awards for Dedication to the SIDS Community” to Debbie Gemmill and Tom Keens. The awards were presented during the Welcome Reception following the Council meeting on October 16, 2019. Michelle Herrera, Chair of the 38th Annual California SIDS Conference, presented the award to Debbie Gemmill, honoring her as the “Poet Laureate for SIDS” in California. Her eloquent poems, essays, and books have been the voice of SIDS...
parents for decades. Jeri Wilson, President of the Southern California Regional SIDS Council, presented the award to Tom Keens, honoring him for his advocacy, teaching, and research in the SIDS Community for over 40 years. Congratulations to both Debbie and Tom.

- **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. Many email servers have changed their firewalls. If you have not received emails from Tom Keens in the past few months, you may be blocking his emails. Please add him as a contact (tkeens@gmail.com), which may prevent his emails from being blocked. Also, check your Spam or Junk email folders for emails from him.

- **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 is a bundle of energy and creative ideas to address SIDS issues in California. Rachel has moved to Las Vegas, Nevada, 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. We asked for California SIDS parents, interested in filling Rachel’s SIDS Parent member vacancy, and three applied. They were interviewed by telephone by the MCAH/CDPH. By California law, members of the Council are appointed by the Director of the California Department of Public Health. We await the decision of the Director to appoint this SIDS parent member of the Council. 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* reported on the SIDS activities of the Maternal, Child, and Adolescent Health (MCAH) Branch of the California Department of Public Health (CDPH).

  - SIDS Council and Southern Regional SUID/SIDS Conference Planning Meeting including the SIDS Coordinators Meeting.
    - Identified and recruited two families to present at the Parent Panel
      - Cristal and Davion Clayton: African American couple who recently had an infant loss. They reside in San Bernardino County
      - Jenn Su and James Lee: Asian American couple who had an infant loss. They reside in Los Angeles County
    - SIDS Coordinators Meeting. Three areas of focus:
      - Safe Sleep education in clinical Setting: Presenters include: Connie Von Kohler (Millers Hospital), Emilie Feenan (Lake County) and Erma Riley (San Francisco County)
      - Local SIDS Program and DSS Child Care Licensing Partnership (Example from the Central Valley)
      - Home Visit (Danielle Sees)

- **Renewed Commitment of SIDS Advisory and addressing California’s Title V Priorities**
  - For parent(s) and families, by offering and providing Grief Bereavement Support Services, and Resources
• Looking into options on providing Peer Support Training.
• Providing the Home Visit webinar presentation than can posted on the CDPH website.
  o Promoting AAP Recommendations and Supporting Safe Sleep efforts by
    • Identifying strategies to address racial disparities: African American and Native American Communities.
    • Working to ensure resources and SIDS trainings.
  o Doctors, nurses, birthing hospitals, and child care setting

• **Department of Public Health/Center for Family Health Safe Sleep Strategy Document:**
  Soon to be released document on the CDPH/Center for Family Health/ Safe Sleep Strategy and Approach. A preview was provided to the Chair of the SIDS Advisory Council for feedback.
  • 1-page document
  • Supports/Promotes 2016 AAP Guidelines
  • Addresses safe sleep disparities
  • Holds family-centered conversations
  • Recommends breastfeeding
  • Educated parents and caregivers about room-sharing and other risk-reduction strategies

• **Interagency Agreement with Sacramento State has been executed**
  o Limited funds in contract, therefore the focus of efforts will be on
    • Annual Conference Planning and Logistics
    • Training Needs and implementation of spring training and two web-based trainings
    • Resources for Families and SIDS Coordinators
  o A concern was addressed regarding the resources and materials on the SIDS website.
    • MCAH will be working with Jeri Wilson and other parents on making the CDPH website more parent-friendly for resources.
  o **Parent Representative on the California SIDS Advisory Council Status:** Awaiting Appointment

• **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. There are problems with respect to SIDS yet to be solved.
**Mission Statement:**

At the July 23, 2019 meeting, the Council adopted the Mission Statement below, to guide our work.

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.
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**Support for SIDS Families by 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. At this meeting, the Council asked Carrie Florez, who keeps data for MCAH/CDPH, if she could give us a rough idea of how many SIDS families receive a home visit from a PHN, and how many receive any contact from a PHN. 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. CDPH/MCAH videotaped Danielle Sees’ outstanding “How to Make a SIDS Home Visit” presentation at the SIDS Coordinator meeting earlier today. This will be produced as a recording that will be online for new SIDS Coordinators to review at any time. This will be an important step toward providing this education to new SIDS coordinators and PHNs.

The California SIDS Program began work on *A Practical Guide for the SIDS Home Visit*, which can serve as a resource guide to public health nurses or other persons making home visits to SIDS families. This is currently being reviewed by Tom Keens, who will write an Introduction and update the scientific information about SIDS. We would then like one or two SIDS Coordinators and/or experienced PHNs who have made home visits to review and update information on how to do this. Danielle Sees and Kitty Roche agreed to take an initial look at this, and help to get it into a cohesive document. We will then have it reviewed more broadly by members of the SIDS community, with hopes of getting this available to the public in the near future.
Newer PHNs, especially those assuming the role of a County SIDS Coordinator, need training and support. Historically, the SIDS Program has provided the names of experienced SIDS Coordinators to serve as a mentor to new SIDS Coordinators. Though this practice is in place, it does not seem that it is well advertised, as some new SIDS Coordinators 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 Dailey, Kitty Roche, and Michelle Scott. This program should be continued and promoted. The SIDS Program website will be updated to include this information.

At our July 23, 2019, Council meeting, 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. We need to improve Coroner Investigator SIDS Training. Heather Griffiths and James K. Ribe agreed to begin this task of developing such a curriculum.

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 in 2020, which is usually in September. 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. Heather Griffiths agreed to work with Tom Keens on this issue.

**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 for a subgroup of SIDS parents to think about what optimal SIDS Parent Support would look lie in California. Lorie Gehrke and Kathleen Beichley volunteered.

Lorie Gehrke wishes to explore creating a live, virtual monthly SIDS support group that she could host (with other skilled support group facilitators) via Zoom once a month. This is a great “outside the box” idea which could be very beneficial to SIDS parents in California and beyond.

SIDS parents who do provide peer support may not be 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. Jeri Wilson was asked to develop a model. Lorie Gehrke and Jeri Wilson will review this and present it, with or without modifications to the Council at our next meeting. We also need to think about how this is done, how often, etc.

**Safe Sleep Education:**

The “Back to Sleep” then “Safe to Sleep” campaigns resulted in dramatic decreases 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 SIDS rates for 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, especially for these high-risk populations. We need to attempt to close the SIDS rate disparity in these high-risk populations. There are racial-ethnic, cultural influences that affect health behavior which I am not sure we understand. We would like to 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? Three recent publications from the Nation Institute for Child Health Quality further indicated that one needs to partner with representatives of these high-
risk groups in order to affect change.\textsuperscript{2,3,4} Rome was not built in a day, and I see this as a long term project. Natalie Adolf, Robin Qualls, Dawn Dailey, Vella Black-Roberts, and Meaghan Neary volunteered to lead this effort.

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? Tom Keens would like a SIDS curriculum in every medical school in California. Kitty Gay agreed to join and promote the same for California nursing schools.

Members of the Council and the California SIDS Community volunteered to take leadership roles in the following projects. These leaders will form working groups to perform these projects. Anyone interested in volunteering for one or more of the above projects is encouraged to do so. Please email Tom Keens (tkeens@gmail.com) to volunteer. The leaders will provide a progress report on their projects at our January 21, 2020, meeting of the California SIDS Advisory Council.

\textsuperscript{2} Applying an Equity Lens to Safe Sleep and Breastfeeding Efforts: Advice from Three Experts. \textit{National Institute for Children’s Health Quality}.

\textsuperscript{3} \textit{It Takes a Community to Save Babies: Successful Strategies for Partnering with Communities of Color}. \textit{National Institute for Children’s Health Quality}.

\textsuperscript{4} How Do We Address Safe Sleep Disparities? Start by Building Trust. \textit{National Institute for Children’s Health Quality}.
### California SIDS Advisory Council Project

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<td>Coroners Referral of all SIDS, SUID, SUDI, Undetermined, ASSB to Public Health for Support.</td>
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### Child Care Issues:

**Susie Fanning**, Licensing Program Manager, Community Care Licensing Division, Fresno Regional Child Care Office, California Department of Social Services, updated the Council on the following childcare issues.

Safe Sleep regulations are pending and are being reviewed at the Office of Administrative Law (OAL), and an additional public comment period will be forthcoming. Regulations will be in effect upon approval. Proposed regulations are on our [website](#) for public review. Outreach is being done through the local field offices to educate providers and stakeholders by way of meetings. In response to three infant deaths in January 2019, the Fresno Regional Child Care Office developed and launched a Safe Sleep training campaign that provided training to
eight counties in English and Spanish reaching approximately 450 providers. The Fresno office utilized Community Care Licensing Division / Child Care Program Safe Sleep Regulation Concepts, and partnered with Fresno County SIDS Coordinator, Lisa Poole, to develop the presentation. All local SIDS Coordinators were invited to the presentations and several attended. This outreach and training model has been shared statewide for presentations in other areas.

The Department has received Federal Block Grant Funding, and additional staffing is ongoing in an effort to inspect all Family Child Care Home and Child Care Center licensees more frequently. The goal is to inspect every facility on an annual basis. Safe Sleep is being prioritized via providing resources and discussion at each inspection and continued engagement with stakeholders. The Department is working toward updating our Safe Sleep brochures and having them translated to additional languages.

Statewide there have been 14 deaths in licensed child care facilities, and an additional 2 were reported to the department that occurred in unlicensed child care environments.

The Department is exploring how we can incorporate Trauma Informed Care in our initial response with providers, children and parents. Training and resources are being reviewed for future implementation.

Tom Keens commented that this work represents a major effort, and that CDSS plus the California SIDS Program, who assisted in some of this work, are to be congratulated and thanked.

**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!


*Venue:* Convention and Exhibition Centre, Brisbane, Queensland, 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.

- **Revised Death Scene Investigation Protocols.**
  The California Death Scene Investigation protocol has been revised by a committee of coroners and a few others. The final version was reviewed by the California State Coroner's Association and then submitted to the MCAH/CDPH for their review and approval. The new version substantially shortens the death scene investigation form without compromising the information obtained. Areas of duplication were removed, and some questions were no longer believed to be relevant. Carrie Florez, at MCAH/CDPH, sent the final draft to the California State Coroner's Association. The protocol is still with them. Heather Griffiths and Tom Keens will meet with CSCA personnel to try to move their approval of the document along, so it can be utilized.
Southern California Regional SIDS Council.

May 2, 2019, Meeting

- Southern California Regional SIDS Council.

  Jeri Wilson, L.C.S.W., President of the Southern California Regional SIDS Council, reported on activities of her Council.

  - Our last meeting was held on August 9th at the Long Beach Department of Health and Human Services. Our next meeting will be held November 14th. At the November meeting, we will vote for Officers. It has been an honor and a pleasure serving as President for the past 2 years.
  
  - I understand that this year’s conference is sold out! I want to take a minute to say thank you to the Southern California Council’s Conference Chair, Michelle Herrera, and Candace Anderson from Sacramento State, for working so hard on planning this year’s event. I am in awe of this venue and looking forward to everything tomorrow.
  
  - The council also wants to thank the San Diego Guild for Infant Survival, Orange County Guild for Infant Survival, Hayden’s Voice, Shaylynn Olivo and Lorie Gehrke for their generous donations. These groups made it possible to have a welcome reception, which is this evening at 5:30 p.m. They also provided scholarships to parents who need support in attending this event.

The Southern California Regional SIDS Council holds four meetings per year. The remaining meeting 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 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 Northern California Regional SIDS Council has not met since our last California SIDS Advisory Council meeting on July 23, 2019, so nothing new to report from the Northern Council. However, we are actively recruiting for nominations for President and Secretary. Elections will be held at our next meeting on November 20th, for a January 1, 2020, effective date.

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 meetings of the Council for the calendar year 2020 will be:

- Tuesday, January 21, 2020; 1:30-3:30 p.m. via telephone Conference Call.
- Tuesday, April 28, 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 4:50 pm.

  Respectfully submitted,

  Lorie Gehrke  
  Vice Chair, California SIDS Advisory Council

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

Minutes: October 16, 2019, Meeting

California Sudden Infant Death Syndrome Advisory Council

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