Mission Statement

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 decreases 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.

Participants

Members Present: Kathleen Beichley; Kris Concepcion; Heather Griffiths; Thomas G. Keens, M.D., Chair; Laurie Hollins; James K. Ribe, M.D., J.D.; Kitty Roche, R.N., P.H.N., B.S.N., M.S.W.; and Jennifer A. Su, M.D.

Members Absent: Dawn E. Dailey, Ph.D., R.N., P.H.C.N.S.-B.C.; and Lorie Gehrke, N.C., Vice-Chair.

State and California SIDS Program: Candace Anderson, C.G.M.P.; Christopher Borges; Carrie Florez; and Mari Taylan-Arculeo, M.P.H.

The meeting was held by telephone conference call. Eight of ten Council members were present. The meeting was called to order at 1:30 p.m., on April 28, 2020.1

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 mandates that people may participate in the conference without identifying themselves in the Minute.

**SIDS Parent Member of the California SIDS Advisory Council**

On April 20, 2020, the Director of the California Department of Public Health appointed Jennifer A. Su, M.D., as a SIDS Parent member of the California SIDS Advisory Council. Jennifer Su replaces Rachel Strickland, who was one of the SIDS parent representatives since 2013. Jennifer Su is a SIDS parent who has been contributing to the California SIDS Community. She spoke on the SIDS parent panel at the 2019 California SIDS Conference. With her husband, she established Aeron’s Foundation (www.aeronsfoundation.org), a nonprofit organization to help SIDS parents by funding funeral costs for newly bereaved families, and for promoting SIDS awareness. She is also a Pediatric Cardiologist at Children’s Hospital Los Angeles, where one of her clinical areas of expertise is sudden cardiac death in infants and children. We are pleased to congratulate Doctor Jennifer Su on her appointment to the California SIDS Advisory Council, and we look forward to working with her.

**Report from the Council Chair**

The California SIDS Community is a robust and vibrant group of people dedicated to helping SIDS families, trying to reduce the number of SIDS deaths by promoting safe infant sleep education, advancing public education about SIDS, and supporting research. I am so proud to be associated with this group of people. More than others, you exemplify the best in the human condition. You support each other and the SIDS Community. I would like to thank you for everything that you do.

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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 used as an inclusive term which includes SIDS, Undetermined, and Asphyxiation Suffocation, and Strangulation in Bed (ASSB). An international group of acknowledged SIDS experts at the 3rd International Conference on Unexplained Death in Infants and Children, held November 26-27, 2018, reinforced and encouraged use of the term "SIDS" for babies who die suddenly and unexpectedly, and they discouraged the several other acronyms that have been suggested (SUID, SUDI, etc.). The California SIDS Advisory Council also endorsed use of the term “SIDS” on January 21, 2020, and recommended that “SIDS” be used.
The California SIDS Advisory Council was established by legislation in 1989, and its membership was fixed at nine members. I am appreciative for those who have chosen to serve on this Council over the years. However, Council members can not do everything that needs to be done for SIDS in California. We need the help of everyone. The Council is an important vehicle by which we can advise the California Department of Public Health on SIDS issues, and I do not want to minimize the contributions of those who are appointed to the Council. However, I hope people do not focus on whether or not they are members of this group. I was actually not a member of the Council until 2006. Prior to that time, I considered myself a Council “groupee”, in that I hung around them, and I continued to contribute, as best I could, to the needs of the California SIDS Community. So, too, we need you all. Do not get caught up on whether you are an appointed member. Rather, as President John F. Kennedy said, “Ask not what your California SIDS Advisory Council can do for you. Ask, rather, what you can do for the California SIDS Community.” I value the input, energy, and enthusiasm of everyone who works to improve SIDS in California, whether or not you are a member of the Council. And, I thank you all for what you have done, are doing, and will do.

Finally, these are challenging times. The COVID19 pandemic has changed the way to live and work. I don’t have the answers how to effectively continue to support SIDS families, especially newly bereaved families, and how to promote safe sleep education in this climate. However, I suspect that some of you have found innovative ways to achieve these goals. In a few minutes, I will invite you all to share your successes and ask for help with your challenges. We can all benefit when we all work together.

California Department of Public Health/Maternal, Child, and Adolescent Health Division

Christopher Borges and 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).

COVID-19

State Staff

- All managers are ensuring coverage at State Offices.
- Program staff are teleworking until further notice.

COVID-19 updates are available on the CDPH website at www.cdph.ca.gov/COVID19.

Infant Safe Sleep Strategies document

- Document released via e-blast to all stakeholders
- Survey was sent early 2020 that asked for help in identify training, tools and other resources to identify resource gaps. Survey is closed and MCAH has compiled results and developing a work plan.

California Birthing and Acute Care Hospitals letter

- This letter is to inform/remind all California birthing hospitals of HSC § 1254.6 & 1596.847. These Health and Safety Codes require all birthing hospitals in California to provide SIDS risk reduction information to all parents or guardians of each newborn, upon discharge from the hospital.
- HSC 1596.847 – this code specifically references the Administration of Child Day Care Licensing, so will be removing reference to this HSC.
• **Tom Keens** added that these regulations apply to all hospitals “caring for infants”, not just birth hospitals. He asked that acute care hospitals and children’s hospitals in California also receive this letter. Some also discharge newborn infants who required NICU care.

• With release of the Infant Safe Sleep Strategies document, the letter has incorporated new information.

• Will be sent through the document review process and once approved will be sent out.

**Spring Trainings**

Virtual Platform

• Friday, April 24th
  o SIDS and Safe Infant Sleep – Tom Keens, MD
  o Compassion Fatigue, Primary/Secondary Trauma, Vicarious Trauma – Michelle Gentle, LCSW, CLEC
  o Coroner/SIDS Coordinator Panel – Heather Griffiths, Deputy Coroner Sacramento County / Sally Eberhard, PHN Stanislaus County / Matthew Dessert, Detective Stanislaus County Coroner’s Office / Judy Melinek, MD, Forensic Pathologist Alameda County

• Monday, May 4th
  o Department of Social Services: Community Care Licensing Division (CCLD), Child Care Program (CCP), Office of Child Abuse Prevention (OCAP) – Susie Fanning, Licensing Program Manager / Stefanie Navarro, Program Analyst / Rene Mancinas, Program Analyst / Marja Sainio, Manager, Family and Community Support Services
  o SIDS Parent Panel - Lorie Gehrke, Laurie Hollins, Brandy Valentine

**Discussion on Statewide Planning for the SIDS Conference**

• Venue: Concord, on October 29, 2020.

• Planning Committee Meeting #2: Thursday, April 30, 2020 - 9 am.

**California SIDS Program**

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

1. Spring Trainings. First segment held 04/24/2020. Well over 200 people attended online. Second segment on March 4 starting at 9:30 a.m. is approaching maximum capacity – pre-registration is required. After second segment, an evaluation and posttest will be sent to participants. Completion of the evaluation and posttest is required for CEUs, which will be distributed after the close of the evaluation response period, and in accordance with participation level. Slides and recordings will be posted after the second segment.

2. Council Meeting platform. We can transition the meeting technology to the Zoom platform, allowing us to alleviate most disruption from feedback, hold music, and background noise. Candace can provide Dr. Keens with the login information which will change for each meeting.
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 in California yet to solve. At our October 16, 2019, meeting the Council identified needs and tasks were generated. A number of individuals volunteered to work on these projects. As a general finding, the COVID19 pandemic has postponed work on many projects. However, progress reports on the projects were given as outlined below.

- **Data on How Many SIDS Parents Receive Visits from Public Health Nurses; Carrie Florez.** She has begun work on this project. Preliminarily, only ~16% of SIDS families received a PHN home visit according to the PHSR forms returned by PHNs. However, these forms are often (usually?) completed when the PHNs are notified of the infant death, and this may be before a home visit is made. Carrie Florez plans to re-survey PHNs at a later date to see if home visits were made after the PHSR was submitted.

- **How to Make a SIDS Home Visit Video (Danielle Sees’ Presentation at the SIDS Coordinator Meeting October 16, 2019).** Christopher Borges, Mari Taylan-Arcoleo and Carrie Florez. This video has been put on the MCAH/CDPH/SIDS website, and it is available for new SIDS Coordinators and PHNs to watch prior to making a SIDS Home visit. To access video, [SIDS health care professional webpage](https://www.cdph.ca.gov/SIDS) (“Webinar”) on the SIDS website ([www.cdph.ca.gov/SIDS](https://www.cdph.ca.gov/SIDS)).

- **Practical Guide to the SIDS Home Visit.** Thomas Keens, Danielle Sees, Kitty Roche, and Theresa Somerville. A version of the Practical Guide to the SIDS Home Visit was sent to Tom Keens. He wrote an introduction and revised his sections on the science of SIDS, including moving the Safe Infant Sleep Recommendations to an Appendix at the end of the document. PHNs should be aware of these, but they should not be a focus of the SIDS Home Visit to educate and support newly bereaved SIDS parents. This modified document was sent to Mari Taylan. She will presumably send it on to Danielle Sees, Kitty Roche, and Theresa Somerville to begin revising the remainder of the document.

- **PHN Mentors for New SIDS Coordinators, Publicize and Include on Website.** Chris Borges and Mari Taylan-Arcoleo. MCAH/CDPH will put this on the website and let all SIDS Coordinators know at the next MCAH Newsletter. Chris Borges checked and said that it was on the website, but it was difficult to find. This is exactly what needs to be modified. Kitty Roche commented that Guen used to call Kitty Roche when new SIDS Coordinators were appointed in Southern California and Dawn Dailey when new SIDS Coordinators were appointed in Northern California. They would then reach out to the new SIDS Coordinators and mentor them as needed. Chris Borges indicated that MCAH/CDPH is usually notified when a new SIDS Coordinator is appointed. Chris Borges, Kitty Roche, and Dawn Dailey will work on a system to identify new SIDS Coordinators and link them with experienced mentors.

- **SIDS Curriculum for Coroner Investigators.** Heather Griffiths James K. Ribe, and Tiffany Williams. In view of the COVID19 pandemic, no progress was made on this. Tom Keens came across some resources which may help you create a curriculum on how Coroner Investigators should interact with newly bereaved SIDS families, which he will share with Heather Griffiths James K. Ribe, and Tiffany Williams. Resources may already exist which can be adapted quickly. It may not be necessary completely to reinvent the wheel.

- **What is the Best SIDS Parent Peer Support: On-line, In-person, One-on-one, Traditional Peer Support Groups?** Lorie Gehrke and Kathleen Beichley. Lorie Gehrke reported at our January meeting that she has the infrastructure in place for an ongoing, monthly, virtual SIDS support group, including the ability to register and manage participants, plus post guides and resources (Thinkific), and to host virtual face-to-face meetings (Zoom). Over the next few weeks, she will work to get content and dates uploaded, so the group can be promoted to SIDS parents around the State. Progress has stalled on this due to the COVI19 pandemic, but she continues to work on this.
• **SIDS Parent Peer Support Training.** Jeri Wilson and Lorie Gehrke. Lori Gehrke reported that Jeri Wilson, Tom Keens and Lorie had emailed to brainstorm about options and would have more to report by the next meeting. However, little has been done in view of the COVID19 pandemic.

• **Closing SIDS Rate Disparities in the African-American Community.** Natalie Adolf, Robin Qualls, Dawn Dailey, Vella Black-Roberts, Meaghan Neary, Laurie Hollins, and Christal Jack.

Meeting convened on November 4, 2019 with Dawn Dailey, Vella Black-Roberts, Meaghan Neary and Robin Qualls to discuss strategies to reduce the SIDS/SUf rates in the Black Community.

Given the importance of this very important issue, the group came to a consensus that we need larger representation from members of the SIDS Advisory Council, Black families and other interested parties.

a) Engage hospital and medical providers serving black families in order to increase/enhance education efforts related to safe sleep practices.

b) Engage black families, whether or not they have experienced an infant loss related to SIDS/SUf in order to validate their experience as it relates to receiving safe sleep information during maternal and pediatric medical visits/appointments. Include Laurie Hollins and Christal Jack as part of workgroup.

c) Review CDPH-MCAH safe sleep guidance upon release.

d) Engage AAP, ACOG, CPSP, RPPC, MCAH Action, CCLHO, WIC Directors, Regional Child Care Providers.

e) How do we ensure that equity and issues related to racism remain at the forefront of this project?

f) Ensure that all Home Visiting Programs are incorporating safe sleep messaging with families (BIH, NFP, HFA, AFLP).

g) How do we ensure that the newly funded MCAH Perinatal Equity Initiative intervention efforts (Doulas, Fathers, Partners) include safe sleep education?

h) How do we embark upon a media campaign to increase awareness and provide consistent messaging?

1) Where do vital registries come into play?

2) Action Items: Robin – Followed up with Mari Taylan on the following:

   a) CPSP – inclusion of safe sleep information at upcoming Spring CPSP annual meeting.


   c) Status of new MCAH SIDS Consultant – Chris Borges has been hired in this position.

   d) SIDS Advisory Council member participation.

   e) Cielo Avalos, MCAH RPPC Consultant – RPPC SOW and Annual Report is adding language on safe sleep for 2019-2022 reporting periods – will share with workgroup

3) Meaghan – will consult with AAP colleague 3.

i) SIDS/FIMR alignment & involvement: reviewing all African-American fetal and infant deaths, making recommendations & bringing to community to develop action plan. Inviting maternal & child health

equity leaders from community such as Dr. Venise Curry winner of the Fresno State’s 2019 Health & Human Services Hero for Advocating for health equity to be part of conversation

j) Incorporating more discussion about culture, disparities, equity, racism, implicit bias, & respectful care into safe sleep presentations

k) Identify potential partnerships: Best Baby Zone, Black Child Legacy, Preg. Care & support group, African American Infant Mortality Blue Ribbon Panel, GLOW, etc.

l) Develop relationships with partners and participate in community events such as baby showers and health fairs

m) Review current curriculum of group facilitators and home visiting programs. Make recommendations at local, state, & national level.

n) Train the Trainer classes: have SIDS leaders/ safe sleep educators reflect the community

p) Next meeting – TBD

• SIDS Curriculum for California Medical Schools and Nursing Schools. Thomas Keens and Kitty Gay. We plan to begin with medical schools and osteopathic medical schools in California. Tasks to be completed are to:
  o Assemble a list of all medical schools and osteopathic medical schools in California.
  o Identify the appropriate contact persons within each school. Should it be the Dean, Curriculum committee, etc.? This is unclear to me at the moment.
  o Our first step should be to survey these schools to see what teaching they currently do. In such a survey, we will also ask if they would like more, and if so what.
  o Kitty Gay already sent out an email to all County SIDS Coordinators asking them for the identity of any medical schools, osteopathic medical schools, and nursing schools in their counties.

Nothing has been accomplished since the last meeting due to the COVID 19 pandemic.

• Revised Death Scene Investigation Protocol: Review and Approval by the California State Coroner’s Association. Heather Griffiths, Thomas Keens, and Carrie Florez. Heather Griffiths has been working with the California State Coroner’s Association (CSCA) on a draft of the Death Scene Investigation protocol, which she thinks is near the point where it will be accepted by CSCA. She is continuing the work with CSCA to approve a final protocol.

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

After thoughtful deliberations, the Organizing Committee of the International SIDS and Stillbirth Conference, along with the respective Boards of Directors of ISPID and ISA, has made the difficult but necessary decision to postpone the Conference to November 11-13, 2021. The 2021 Conference will be in Brisbane, Australia.

This decision was not made lightly. There was concern that there will still be widespread travel bans and states of emergency for several months, making conference planning difficult, both for the planning committees and
for potential attendees. We also do not take the severity of this pandemic lightly, and there was a strong feeling that it is our responsibility to protect the health and safety of our attendees, exhibitors, sponsors, and staff.

We appreciate that this is disappointing news to all of you who were looking forward to coming to Brisbane later this year to share and advance the scholarship in the areas of stillbirth and sudden unexpected death in infancy. However, we do look forward to an excellent Conference in 2021.

We are very grateful for your support of ISPID. Please stay safe and well.

With our best regards,

The ISPID Board of Directors

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**Providing Support to SIDS Families and Safe Infant Sleep Education in the COVID19 Era**

**Support for Newly Bereaved SIDS Families (SIDS Home Visit)**

April Myers, a SIDS parent and President of the Guild for Infant Survival, Orange County, reported on their active SIDS Parent Support group, which until recently was held person-to-person in Laguna Beach. Since the COVID19 isolation, the group met for the first time on April 27, 2020, by ZOOM. April reported that the meeting went well, and that families relatively quickly overcame the technology barriers and were able to interact as they often do. She viewed this as a success. However, she did emphasize that there is no substitute for a face-to-face meeting, and that this group will return to face-to-face meetings once COVID19 restrictions are lifted.

A number of SIDS Coordinators commented that they were trying to make SIDS home visits by telephone. Few were using ZOOM or another computer virtual platform. Most did not feel this experience was as good as an in-person visit. In many cases, PHNs did not have the correct phone number or could not connect with them by telephone. Some tried multiple ways to find SIDS families. In general, these SIDS Coordinators would prefer to return to in-home person-to-person visits.

**Safe Infant Sleep Education.**

Donna Dichirico and Pat Spear, Program Managers for the Regional Perinatal Programs of California, presented how the RPPC is working with hospitals to improve safe infant sleep education. RPPC is a key stakeholder of California’s community-based comprehensive perinatal health system. RPPC’s mission is to ensure that mothers and babies are receiving the right care at the right time, and to prevent avoidable long-term or permanent disability or mortality.

We are continuing with hospital site visits via the Zoom Platform. The State focus this year is on Maternal Levels of Care, SIDS, Breastfeeding as well as SB464 & AB241. We encourage the hospital’s Quality Improvement to include these areas and assist them in implementation of any QI activities that provides Best Practices.

Doctor Daniel Hershey, Professor of Pediatrics at UCSD, and a Hospitalist at Rady Children’s Hospital of San Diego, described his program to improve safe infant sleep in his acute care Children’s hospital, and to extend this to other hospitals in San Diego. He mentioned that U.S. News & World Report, which conducts an annual influential ranking of hospitals across the country, has now included safe infant sleep guidelines as part of the criteria for determining a hospital’s ranking. He sent Tom Keens the specific requirements, which are shown below.
Providing the following elements of a “Safe Sleep” program (F8.1):

<table>
<thead>
<tr>
<th>Element</th>
<th>Points</th>
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<tbody>
<tr>
<td>Mandatory Safe Sleep Education for NICU Staff</td>
<td>4</td>
</tr>
<tr>
<td>Required documentation that Safe Sleep has been discussed with family prior to discharge</td>
<td>4</td>
</tr>
<tr>
<td>Policy in place for use of devices (swings, infant seats, etc.)</td>
<td>4</td>
</tr>
<tr>
<td>NICU-based written criteria for Safe Sleep within NICUs</td>
<td>4</td>
</tr>
<tr>
<td>Engaging in Safe Sleep auditing to ensure that patient sleep environment and position is appropriate for safe sleep practice (F8.2)</td>
<td>1</td>
</tr>
<tr>
<td>Monitoring compliance with NICU-based Safe Sleep policy at least weekly or at least bi-weekly (F8.3)</td>
<td>1</td>
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Hospitals across the country strive to achieve the highest ranking they can, so including safe infant sleep as part of the criteria may motivate more hospitals to adopt rigorous safe infant sleep policies and programs.

Although Alameda County has not had a SIDS/SUIDS infant death since February 2020, the Alameda County Public Health Dept. SIDS Coordinator, *Vella Black-Roberts*, has been focusing on providing outreach and training to the Alameda County child care community, Comprehensive Perinatal Services Program (CPSP), and MPCAH case managers. She has also been conducting outreach to hospitals to educate medical staff/health care workers about the law requiring that they provide SIDS/SUIDS education to pregnant clients. That outreach included trainings for one local hospital OB-GYN nurses – both evening and day shifts. However, trainings scheduled for March and April were postponed due to the Shelter in Place, and they will be rescheduled once the County’s “Shelter in Place” (SIP) order is lifted. Similarly, most counties have postponed safe infant sleep education due to the COVID19 pandemic for the same reasons.

*Kitty Roche*, President of the Southern California Regional SIDS Council, reported on activities of her Council.
The Southern California Regional SIDS Council met on February 20, 2020, at the Department of Health and Human Services in Long Beach. Minutes were approved from November’s meeting. Reports were received from Chris Borges, California Department of Public Health, Candace Anderson from SIDS Contract Support at CSUS, Dr. Keens with the California SIDS Advisory Council, and various community reports. As we were unable to elect new officers in November, due to a reluctance to volunteer, elections were held at this meeting. After much discussion, Kitty Roche, PHN, BSN, MSW was elected President; Susana Aceves, RN, BSN, PHN, from Long Beach is our new Vice President; and Joey Kiang, USC student intern with Dr. Keens, is our Secretary.

I have not had time to reach out to the SIDS Coordinators during the pandemic to hear how you are all providing support to our SIDS Community during this crisis and would appreciate some emails describing your process. Thank you, and I look forward to the next 2 years.

The Southern California Regional SIDS Council holds four meetings per year. At least the next meeting will be held virtually on May 14, 2020. After that, the remaining meetings for 2020 may be held at the Department of Health and Human Services, City of Long Beach, 2525 Grand Avenue, Long Beach, California 90815, on August 13, 2020; and November 19, 2020, at 10:00 a.m.-1:00 p.m.

Kitty Roche (phone: 760-390-4576; Kittyr065@gmail.com)

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Kitty Roche (phone: 760-390-4576; Kittyr065@gmail.com)

Laurie Lawson, President of the Northern California Regional SIDS Council, reported on activities of the Northern California Regional SIDS Council. However, she did not submit a written report for these minutes.

2020 California SIDS Advisory Council Meetings

The remaining meetings of the California SIDS Advisory Council in 2020 are:

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

- In-person meeting on Wednesday, October 28, 2020, 3:30-5:30 p.m., at the Crown Plaza Concord/Walnut Creek Hotel, in Concord, California. This is the day before the 39th Annual California SIDS Conference.

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 3:15 p.m.

Respectfully submitted,

Lorie Gehrke
Vice Chair, California SIDS Advisory Council

Thomas G. Keens, M.D.
Chair, California SIDS Advisory Council
California Sudden Infant Death Syndrome Advisory Council

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