



# California Sudden Infant Death Syndrome Advisory Council

## Minutes of the April 30, 2013, Meeting

### Members of the Council

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

**Lorie Gehrke,** *Vice Chair,*  
*SIDS Parent.*

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

**Kathleen Beichley,** *SIDS*  
*Parent*

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

**Yolanda DeMello,** *SIDS*  
*Parent*

**Steven Durfor,** *Police/Fire*  
*First Responder.*

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

**Dennis H. Watt,** *Coroner.*

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

**Aline Armstrong, P.H.N.,**  
*President, Northern Calif.*  
*Regional SIDS Council.*

### Council Chairperson:

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

[tkeens@chla.usc.edu](mailto:tkeens@chla.usc.edu)  
[tkeens@gmail.com](mailto:tkeens@gmail.com)



**California SIDS Advisory Council**  
**Los Angeles, California, October 29, 2012**

- **Members Present:** Thomas G. Keens, M.D., *Chair*; Lorie Gehrke, *Vice Chair*; Kitty Roche, *Secretary*; Dawn Dailey, RN, PHN, PhD; James K. Ribe, M.D.; and Penny F. Stastny, R.N., B.S.N.
- **Members Absent:** Aline Armstrong, P.H.N.; Kathleen Beichley; Yolanda DeMello, M.S.P.M; Steve Durfor; and Dennis Watt, Coroner.
- **State and California SIDS Program:** Sandra, Bahn; Gwen Edelstein, RN, PNP, MPA; Carrie Florez; Cheryl McBride, RN; and Guey-Shiang Tsay, RN, MSN.
- **Guests:** Luz Arboleda-Babcock, P.H.N.; Catherine Farnham, R.N., P.H.N.; Devra Hutchinson; Karen Jackson, R.N.; Colleen Ma, C.L.E.; Sherry Nolan, R.N.; Danielle Sees, R.N., P.H.N.; Jessica B. Spearman; Darci Torres; and Robert Torres.
- The meeting was held by telephone conference call. The meeting was called to order at 1:32 P.M., on April 30, 2013.
- **Introductions.**  
Council members, state staff, and guests introduced themselves.



- **California SIDS Program.**

**Cheryl McBride, R.N.**, Program Manager of the California SIDS Program will retire on April 30, 2013. She has served as the Program Manager for nearly 16 years. On behalf of the California SIDS Advisory Council, she was awarded its *SIDS Lifetime Achievement Award* at the California SIDS Program's SIDS Training for Public Health Professionals and Emergency Responders in Bakersfield on April 18, 2013. The Council thanks *Cheryl* for her years of devoted service to the California SIDS Community, and we wish her the best that life has to offer in her retirement. She will continue to work limited hours for the California SIDS Program through June 30, 2013.



**Gwen Edelstein, R.N., P.H.N., P.N.P., M.P.A.**, Program Director of the California SIDS Program, announced that she will also retire on June 30, 2013. She has directed the California SIDS Program for 20-years. She was the recipient of the *Daniel E. Boatwright Award* for “extraordinary public service on behalf of Californians touched by sudden infant death syndrome” in 2004. Under her leadership, the California SIDS Program has become a model program for providing SIDS services and education, and supporting SIDS research in California. The past two decades have seen monumental changes in SIDS, primarily with the advent of SIDS Risk Reduction Recommendations and a huge drop in the number of SIDS babies who died. Yet, SIDS babies continue to die, and *Gwen* has masterfully navigated the turbulent waters of budget cuts, sustaining support for SIDS families, and instituting innovative education programs to reduce the risk of SIDS. The Council thanks *Gwen* for her 20-years of devoted service to the California SIDS Community, and we wish her the best that life has to offer in her retirement.



California State University Long Beach (CSULB) Research Foundation currently holds the contract for the California SIDS Program through an interagency agreement with CDPH MCAH. The contract has been a noncompetitive renewal contract since 1996 when *Gwen* assumed the position of California SIDS Program Director for this contract. The Foundation plans to terminate the contract effective June 30, 2013 which coincides with *Gwen's* retirement date.

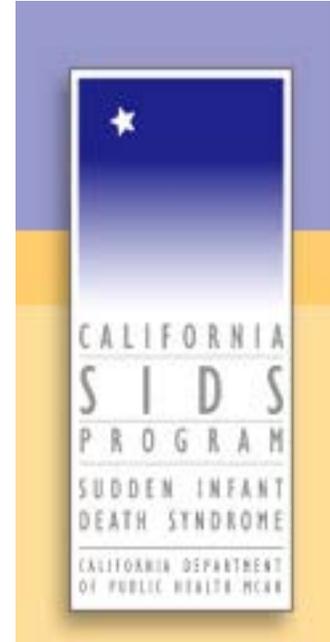
This is problematic, as we are given only two months to find a new contractor and put a program in place.

*Gwen Edelstein* acknowledged and thanked the Northern/Southern Regional SIDS Councils and California State SIDS Advisory Council for their support of the California SIDS Program and all their work in advancing SIDS services, education and research in California. She noted that the Program's accomplishments made during her years as Program Director were possible because of the mutual partnerships and collaborative associations that evolved over the years with countless agencies/organizations, professionals, individuals and SIDS parents/family members at the local, state and national level. She recognized CSULB Research Foundation for

their guidance with all aspects of the CDPH MCAH contract and thanked the exceptional staff members including *Cheryl McBride* and *Susan Moore* who dedicated themselves to serving the CA SIDS Community. *Gwen* will work with CDPH MCAH to prioritize scope of work activities and assist, counsel and support CDPH MCAH during the Program's transition.

*Gwen Edelstein* submitted a detailed written report of California SIDS Program activities for January 1 to March 31, 2013, that was distributed to all Council members and will be posted on the Program's website.

- *Gwen* discussed the major revisions made to update the Reducing the Risk section of their website so that it reflects the 2011 AAP risk reduction recommendations/safe sleep guidelines and the new Safe to Sleep Campaign materials. Outdated resources on the website have been deleted and/or replaced and new linkages added to access national agencies such as the American Academy of Pediatrics, NICHD Safe to Sleep Campaign, National SIDS/SUID Resource Center and First Candle. In addition the Support and Services pages of the Grief/Bereavement section were reviewed and needed changes made to the national, state and local support group listings including meeting information, contact information, social media options and linkages to emails/websites
- *Gwen* reported there were 167 attendees for the Southern California SIDS Training for Emergency Personnel and Public Health Professionals held on April 18<sup>th</sup> in Bakersfield. There were a total of twenty nine (29) agencies/organizations represented from twelve (12) counties including; Alameda, Contra Costa, Fresno, Humboldt, Kern, Kings, Los Angeles, Madera, Orange, San Diego, San Luis Obispo, and Ventura. A total of nine (9) county local health jurisdictions and the City of Long Beach were represented by a PHN and/or SIDS Coordinator. Jurisdictions denoted in bold italics in the above listing were represented by a SIDS Coordinator and those in bold had PHNs in attendance. The overall rating for the training averaged between excellent and very good. *Michelle Curioso*, SIDS Coordinator Kern County, was instrumental in working with the Kern Regional Center to secure the meeting space and accommodate the Program's training needs. Because of her extensive solicitation and recruitment efforts, numerous agencies in Kern County had professionals/paraprofessionals in attendance. *Gwen* acknowledged the support received for this training from several Council members. *Steve Durfor* assisted in advertising this event by circulating the email announcement to members of the Sheriff's Association and California State Coroner's Association. *Thomas G. Keens, MD* provided the morning overview of current research theories and the SIDS risk reduction/safe sleep update in the afternoon. Both sessions were exceptional and received excellent reviews. Deputy Coroner *Dennis Watt* Placer County presented a comprehensive overview of the role of first responders/coroners when an infant dies suddenly and graciously assisted with registration. *Susan Moore* also assisted with registration and facilitated the discussion of the tasks of grieving as *Maureen Chavez*, *Christina Thiele* (SIDS parents) and *Vanessa Solis* (SUDC licensed child care provider) shared their journey of loss. *Scott Herring*, Department of



Social Services (DSS) Northern/Central California Child Care Advocate Community Care Licensing, presented the role of DSS licensing when an infant dies in a licensed child care facility and discussed their investigative/reporting responsibilities. *Gwen* thanked those who had a part in making this training a highly successful educational event

- During this report period, *Gwen* shared that there were newly appointed SIDS Coordinators for Kings, Colusa, Madera, Mendocino, Tuolumne and San Luis Obispo counties and the City of Long Beach. The California SIDS Program continues to provide new coordinators with the *SIDS Handbook for Public Health Professionals*. *Kitty Roche* or *Dawn Dailey*, the PHN State SIDS Advisory Council representatives, provided a welcome orientation which was greatly appreciated by the Coordinators receiving their calls.
- *Cheryl McBride* prepared the January to March 2013 Compliance Monitoring Report and Presumed SIDS Cases' Report for 2012 and 2013 by County of Residence which reflects infant deaths through April 22, 2013. All of these reports were distributed to members and will also be posted on the Program's website.

- **State Report.**

*Guey-Shiang Tsay* presented a report of the California SIDS activities of the Maternal, Child, and Adolescent Health Section of the California Department of Public Health.

- The Northern California SIDS training for Emergency Personnel and Public Health Professionals on January 24, 2013 in Sacramento and the Southern California SIDS training for Emergency Personnel and Public Health Professionals in Bakersfield on April 18, 2013 were successful. Big thanks to Michelle Curioso from Kern's county and all the key speakers and SIDS parents, and Gwen Edelstein and Cheryl McBride for their efforts and contributions on the trainings.
- We wish all the best for Gwen and Cheryl's retirement and appreciate their contributions to the CA SIDS program.
- CSULB Foundation has sent MCAH an early termination notice ending the contract effective June 30, 2013. This early termination of the SIDS program contract will result in a significant impact on the MCAH SIDS program. We are currently focusing on finding a new Contractor. I invited my supervisor, Sandra Bahn, to join our meeting and she will provide some information on this issue.

*Sandra Bahn*, MCAH Policy Section, presented a report of the California SIDS activities of the Maternal, Child, and Adolescent Health Section of the California Department of Public Health.

- MCAH is committed to continuing the *California SIDS Program*.



- We are pursuing an Interagency Agreement with a University of California or California State University. This would be the fastest way to continue SIDS services with as little interruption as possible.
- Ideally, there will not be a gap in services; but with the short timeframes to work around a gap is a possibility
- The October SIDS Conference may be impacted (delayed) by the contracting process. It is too soon to know if the 2013 Conference can be held as planned.
- There are challenges ahead!
  - Short timeframe for contracting as current contract ends June 30, 2013.
  - Website – may not be accessible or not maintained until the Department can bring it in-house.
  - Finding the right Contractor.
  - Funding for the contract has been ~\$300,000 per year.
- **SIDS Risk Reduction Education.**

#### **Los Angeles County Infant Safe Sleep Campaign.**

The ICAN LA County Infant Safe Sleeping Campaign: Safe Sleep for Baby has spent the first quarter of 2013 preparing for Safe Sleep for Baby Campaign Launch event. The launch event will be held at California Hospital, on Wednesday, May 8, 2013. Materials to be debuted at the launch, including a Safe Sleep for Baby PSA in English and Spanish, Radio Spots in English and Spanish and outdoor advertisements in English and Spanish, have all been created and completed during the first this first quarter of 2013. Additionally, a new informational pamphlet and re-vamped website will also be launched at the Press Conference.

The Safe Sleep for Baby 30-minute e-learning course has also been completed during the first part of the year. The e-learning course can be found on the LA County SABA training system offering number: 00328751 and on ICAN's SafeSleepForBaby.com website.



**Jessica B.  
Spearman**



ICAN Associates in partnership with First 5 LA have spent the remainder of the first quarter of 2013 partnering with stakeholder agencies for the Safe Sleep for Baby Campaign Partnerships. Agencies are asked to partner with the campaign and use campaign materials to educate staff about infant safe sleeping practices and urge staff to share infant safe sleeping information and tips with the families they work with. To date, ICAN Associates in Partnership with First 5 LA have partnered with the 12 Los Angeles Child Abuse Councils and with the ICAN Policy Committee members. Additional, city, community based organizations, hospitals and health care centers will be reached out to in the coming months. At the April 19, 2013 ICAN Policy Committee meeting the LA County Department of Corner acknowledged our Safe Sleep for Baby Policy Action item and Safe sleep for Baby campaign. We have gained full support from the ICAN Policy Committee.

ICAN would like to request all California SIDS Advisory Council Members that are interested in Partnering with ICAN, to please e-mail us at [info@safesleepforbaby.com](mailto:info@safesleepforbaby.com).

All Safe Sleep for Baby Training materials, including the Safe Sleep for Baby Training Tool Kit, e-learning course, "A Space of My Own: Reducing Infant Sleep-Related Infant Deaths in LA County: Training Video # 1 and more can be found online at:

[SafeSleepForBaby.com](http://SafeSleepForBaby.com).



- **SIDS, Undetermined, or SUID Diagnoses.**

There was no discussion on this issue.

- **Council's Role in SIDS Parent Support.**

*Lorie Gehrke* (Northern California SIDS Alliance) stated that she is texting a lot as a way to connect with bereaved parents. She may be starting a SIDS support group in Walnut Creek. *Colleen Ma* (Guild for Infant Survival, Orange County) reported that she is providing online grief support.

- **Public Health Nurse Issues.**

*Dawn Dailey* (Contra Costa County) reported that by reaching out to the new SIDS Coordinators, especially those who are MCAH Coordinators/Directors, it tends to invigorate the population based level of support/services. *Penny Stastny* (Orange County and Los Angeles County) shared that even with PHN referrals to local support groups, fewer families are coming to the meetings. *Kitty Roche* (San Diego County) shared that in San Diego County they are

training *Michelle Herrera*, a Spanish speaking SIDS parent, as a peer counselor. *Luz Arboleda-Babcock* (Los Angeles County) shared that she is also Spanish speaking, and she does make phone contact with SIDS/SUID families in Los Angeles County.

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

There was no discussion on this issue.

- **Southern California Regional SIDS Council.**

*Penny F. Stastny, R.N., B.S.N.*, President of the Southern California SIDS Council, reported on the activities of the *Southern California Regional SIDS Council*. The last *Southern California Regional SIDS Council* meeting was held on February 7, 2013. At that meeting, thirteen members were present, including our five SIDS Coordinators from Orange, Los Angeles, Long Beach, Ventura, and San Diego Counties. Three SIDS parents, Maureen Chavez, Jeri Wilson, and Colleen Ma were in attendance. Doctors Ribe, Keens, and Chana Chin (Pediatric Pulmonology Fellow at CHLA/USC) were also present. The next three meetings in 2013 will be held May 9; August 8, and November 14, 2013.



**Southern California Regional SIDS Council.  
February 7, 2013**

At our last State SIDS Council on January 22, 2013, the Presidents from both Regional Councils were asked to query our members to see if they experienced problems by SIDS parents by first responders. At our meeting February 7<sup>th</sup>, we asked the SIDS Coordinators and SIDS parents for their input:

- Los Angeles County has had problems primarily due to the fact that suspected SIDS deaths are referred to the Department of Child and Family Services (DCFS). There were no problems perceived from first responders law enforcement.
- San Diego County reported no problems.
- Riverside County reported some possible problems.
- Orange County reported only one known negative response from police.

Discussion took place about this issue of first responders doing an investigation without sensitivity or conveying an accusatory tone during their investigation. It was noted that some police officers only responded to one or two infant deaths in their entire career, so they may not have the experience or knowledge to respond effectively or sensitively. A suggestion was made

that maybe a chaplain or a TIP (trauma intervention program) volunteer would help. But, not all counties have these services available.

Kitty Roche, San Diego County, shared that there were more complaints about the hospital personnel than about first responders.

Doctor Ribe commented that the Los Angeles Coroner’s response is a “First Responder” call. In Los Angeles law enforcement (LAPD or Sheriff’s Division) usually defers to *Denise Bertone*, coroner’s investigator, to do the interview, and so there are usually no complaints. DCFS has become much more aggressive regarding infant deaths and bringing families into dependency court, questioning them; “Is this a safe household?” In Los Angeles, even “presumptive SIDS” deaths are being followed by lawyers and questioned about the case. One mother in particular has been very unhappy with her treatment by the system. This is very troublesome to the SIDS community in Los Angeles. The Los Angeles County Board of Supervisors is involved, pressuring DCFS and being watched and demanding they be more aggressive.

According to Dennis Watt, Sheriff/Coroner representative to the California SIDS Advisory Council, the POST SIDS training module is still being shown to new incoming cadets.

Thus, in general, it seems that parent complaints come more from mandatory DCFS involvement in Los Angeles deaths than from first responder law enforcement officers themselves.

**CHLA Pilot Project on “Infant Safe Sleep”:** Two first year pediatric residents at Children’s Hospital Los Angeles, *Doctors Sandy Gildersleeve and Manu Raam*, have embarked upon a 3-year project to improve safe infant sleeping conditions for inpatients at CHLA, and to improve parent education on safe infant sleep both for infants discharged from the hospital and for infants seen in our outpatient clinics. Currently, there is no consistent way in which infant safe sleep education is given to patients, if it is given at all.



**Sandra Gildersleeve, M.D.**    **Manu Raam, M.D.**    **Myrel Catbagan, R.N.**    **Leslie Greene, R.N.**



Further, infants hospitalized often have blankets, pillows, stuffed toys, etc. in their cribs. CHLA has now begun this pilot program on one of the inpatient wards (5-East). 5-East nurses, particularly *Myrel Catbagan*, *Leslie Greene*, *Chris Lins*, and *Sherry Nolan* have been participating, and *Penny Stastny* has been serving as a nurse consultant. *Doctor Thomas Keens* continues to oversee this “Infant Safe Sleep” project, and he positively encourages all physicians and nurses involved. The project started with a current assessment of nurse and physician knowledge and practices, crib audits, and parent surveys. An educational intervention was performed as part of the annual 5-East Nursing Education Day, on April 10, 16, and 23, 2013. A reassessment of the knowledge and practices will follow after a period of time for education. Once the program has been established on 5-East, it will be extended to the entire hospital. The physicians and nurses working together have come up with innovative ideas.

The initial educational day presentations were hugely successful. The team created a **S-A-F-E** logo, which stands for Supine, Alone, Firm mattress, and Empy crib. Laminated versions of this were created so each 5-East nurse could have one attached to their ID badges. The program will expand to include laminated posters at each bed for any infant admitted to the hospital under one-year of age.

One exciting opportunity of this project has been to create a safe infant sleep policy for children’s hospitals which care for children with a variety of chronic disorders. Existing protocols are for hospitals giving birth to normal newborn infants. However, many infants with chronic disorders may have medical complications which complicate safe infant sleep recommendations.

**Community Reports** were given by all five of the SIDS Coordinators in their prospective jurisdictions. Educational trainings, handouts on Safe Infant Sleep are all being done and “presumptive SIDS” cases are being followed up. Southern California SIDS Parent support groups in Los Angeles, Orange, San Diego, and Riverside counties are active.

- **Northern California Regional SIDS Council.**

*Aline Armstrong, P.H.N.*, President of the Northern California Regional SIDS Council, was not present to report on activities of the *Northern California Regional SIDS Council*.

The remaining meetings for calendar year 2013 will be May 17<sup>th</sup>, July 19<sup>th</sup> and November 15<sup>th</sup> 2013.

The Northern California Regional SIDS Council is informing everyone to save the dates of October 3-4, 2013, for the 33<sup>rd</sup> *Annual California SIDS*



Northern California Regional SIDS Council,  
February 1, 2013.

*Program Fall Conference*, which is scheduled to be held at the California Department of Public Health in Sacramento, California.

- **Council Meetings in 2013.**

The remaining *California SIDS Advisory Council* meetings for 2013 are:

- Meeting by telephone conference call, Tuesday, August 13, 2013, 1:30-3:30 P.M.
- In-person Meeting: Thursday, October 3, 2013, 1:00-4:00 P.M., the day before the 33<sup>rd</sup> *Annual California SIDS Conference* in Sacramento, California.

By law, meetings of legislatively mandated advisory councils are open to the public. Therefore, anyone interested in participating in *California SIDS Advisory Council* meetings is welcome and encouraged to attend.

- **Adjournment.**

The meeting was adjourned at 2:55 P.M.

Respectfully submitted,

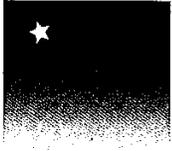
Kitty Roche, R.N., P.H.N., B.S.N., M.S.W.  
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Gwen Edelstein, R.N., P.N.P., M.P.A.  
Program Director, California SIDS Program



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CALIFORNIA  
SIDS  
PROGRAM  
SUDDEN INFANT  
DEATH SYNDROME  
CALIFORNIA DEPARTMENT  
OF HEALTH SERVICES MCAH

April 25, 2013

Dear California State SIDS Advisory Council and Northern/Southern California Regional SIDS Council Members:

After much thought and deliberation, I have decided to retire as Program Director for the California SIDS Program/California State University Long Beach (CSULB) Research Foundation effective June 30, 2013. I am at that point in my life after twenty (20) years with the California SIDS Program, I want to realize my personal life goals and have chosen to make that a priority rather than my professional career.

For the past seventeen (17) years, CSULB Research Foundation has served as the contractual agency to administer the California SIDS Program for the California Department of Public Health (CDPH) Maternal, Child and Adolescent Health (MCAH) Division. As California SIDS Program Director, I have been part of this outstanding organization and have had the pleasure of working with a dedicated, helpful and supportive team of individuals. I am truly grateful for the Foundation's exceptional leadership, expert guidance, unwavering support and ongoing assistance with all aspects of our State contract.

I have enjoyed a very rewarding and fulfilling professional career with the California SIDS Program. During my tenure, we have worked collaboratively with CDPH MCAH to identify and implement scope of work activities to address and serve the ever changing needs of the California SIDS Community. In the past two decades, we have made major progress in reducing the incidence of SIDS in California; strived to develop and implement exemplary education and training programs; worked diligently to promote SIDS awareness through risk reduction/safe sleep outreach activities; and most importantly, endeavored to enhance supportive services to those involved with and affected by the sudden unexpected death of an infant. This has been possible because of the mutual partnerships and collaborative associations that evolved over the years with countless agencies/organizations, professionals, individuals and SIDS parents/family members at the local, state and national level.

The Northern/Southern Regional SIDS Councils and California State SIDS Advisory Council have played an instrumental role in the California SIDS Program's ability to fulfill our mission and meet mandated goals/objectives. Council members have unselfishly provided expert guidance, ongoing technical assistance and invaluable support. It has been an honor and privilege to have worked with all of you. Your dedication and caring have truly made a difference in advancing SIDS services, education and research in California. With CDPH MCAH at the helm and the State Council's guidance under the stellar leadership of Dr. Thomas G. Keens, Council Chair, and the visionary legislation that set the foundation for services and support, the California SIDS Program will in the years ahead continue to serve the California SIDS Community in an exemplary fashion.

In the coming months we will work with CDPH MCAH to prioritize and complete our contractual obligations and scope of work activities. I will do all I can to assist, counsel and support CDPH MCAH during the Program's transition. Although I look forward to retirement, it saddens me to be leaving the Program. I will miss the personal and professional relationships I have developed along the way. I wish you well and greatly appreciate the opportunity to have been a part of the California SIDS Program's accomplishments and to have worked with the California SIDS Community.

Sincerely,  
  
Gwen Edelstein, RN, PHN, PNP, MPA  
Program Director

California Sudden Infant Death Syndrome Program

California Sudden Infant  
Death Syndrome Program  
11344 Coloma Road  
Suite 560  
Gold River, California  
95670-6304  
916-851-SIDS (7437)  
800-369-SIDS (7437)  
FAX 916-851-5937  
info@californiasids.com  
www.californiasids.com

# California SIDS Advisory Council



Kathleen Beichley



Dawn Dailey



Yolanda DeMello



Steve Durfor



Lorie Gehrke



Tom Keens



James Ribe



Kitty Roche



Dennis Watt



Penny Stastny



Aline Armstrong

