



# REFLECTIONS

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## A Note From The President

I have found that the last 5 ½ years have brought me to a different place. I'm able to wake up each day. I'm able to smile and enjoy the beauty in what life has to offer. At my son's funeral I played a new song that had just come out on the radio called "With Hope". I have included the lyrics to that song below. I know that nothing we do will ever bring our babies back but I hope that " WITH HOPE" you can move forward taking each second, minute, hour, day as it comes.

### With Hope

by Steven Curtis Chapman

This is not at all how  
We thought it was supposed to be  
We had so many plans for you  
We had so many dreams  
And now you've gone away  
And left us with the memories of your smile  
And nothing we can say  
And nothing we can do  
Can take away the pain  
The pain of losing you, but ...  
We can cry with hope  
We can say goodbye with hope  
'Cause we know our goodbye is not the end, oh  
no  
And we can grieve with hope  
'Cause we believe with hope  
(There's a place by God's grace)  
There's a place where we'll see your face again  
We'll see your face again

And never have I known  
Anything so hard to understand  
And never have I questioned more  
The wisdom of God's plan  
But through the cloud of tears  
I see the Father's smile and say well done  
And I imagine you  
Where you wanted most to be  
Seeing all your dreams come true  
'Cause now you're home  
And now you're free, and ...

We have this hope as an anchor  
'Cause we believe that everything  
God promised us is true, so ...

So we can cry with hope  
And say goodbye with hope  
We wait with hope  
And we ache with hope  
We hold on with hope  
We let go with hope

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This song was one of a couple of reasons why I named my subsequent baby Hope. Words cannot express the pain of losing them. But there is one thing we can do. We will remember them forever. I'm 5 ½ years out and I will forever cry with hope.....

Rachel

*honored. I hesitated before offering to help, because I wasn't certain help was something he wanted. Once approached, he happily shared the task. As we quietly made our way throughout the area, I was overwhelmed with a tremendous sense of peace and love. This man, with each step, restored faith in my shattered world. He explained that he had been coming to El Toro Memorial Park for years. We placed an egg at Ryan's marker and I shared that Ryan had died from SIDS. After telling my story, I summoned the courage to ask him if he had lost a child or grandchild. The answer was no. I just looked at him, surprised by his reply. He then explained, "I come here so the children know they haven't been forgotten."*

*That Easter Sunday, we met a family during our visit with Ryan. The woman beamed as she saw the eggs and made a point of telling me that El Toro Memorial Park always puts out eggs for the children each year. She said that it brings great happiness to her family, especially her daughter, who had also lost a child. I just listened and smiled---now knowing, there are angels here on Earth.*

If you would like to contribute to our "Parent's Corner", email your submission to [lbiakanja@yahoo.com](mailto:lbiakanja@yahoo.com).



## Parent's Corner

By Jordy Jahn~~Ryan's Mommy

*A few days before what would have been Ryan's first Easter, I observed an older man making his way around the children's section of El Toro Memorial Park with brightly colored plastic eggs. He was indeed quite elderly, yet managed to handle the terrain even in the rain. With umbrella in one hand, he read each and every marker, carefully placing a plastic egg for each child. If there were twins or triplets, he made sure each was*

### Safe Sleep Environment

- ◆ Place your baby in a safety-approved crib with a firm mattress and a well-fitting sheet (cradles and bassinets may be used, but choose those that are JPMA (Juvenile Products Manufacturers Association) certified for safety).
- ◆ Place the crib in an area that is always smoke free.
- ◆ Don't place babies to sleep on adult beds, chairs, sofas, waterbeds, or cushions.
- ◆ Toys and other soft bedding, including fluffy blankets, comforters, pillows, stuffed animals, and wedges should not be placed in the crib with the baby. These items can impair the infant's ability to breathe if they cover his face.
- ◆ Breastfeed your baby. Experts recommend that mothers feed their children human milk at least through the first year of life.



## Apnea, Sudden Infant Death Syndrome, and Home Monitoring

Committee on Fetus and Newborn *Pediatrics* 2003;111:914-917

**ABSTRACT.** More than 25 years have elapsed since continuous cardiorespiratory monitoring at home was suggested to decrease the risk of sudden infant death syndrome (SIDS). In the ensuing interval, multiple studies have been unable to establish the alleged efficacy of its use. In this statement, the most recent research information, concerning extreme limits for a prolonged course of apnea of prematurity is reviewed. Recommendations regarding the appropriate use of home cardiorespiratory monitoring after hospital discharge emphasize limiting use to specific clinical indications for a predetermined period, using only monitors equipped with an event recorder, and counseling parents that monitor use does not prevent sudden, unexpected death in all circumstances. The continued implementation of proven SIDS prevention measures is encouraged.

### Recommendations

1. Home cardiorespiratory monitoring should not be prescribed to prevent SIDS.
2. Home cardiorespiratory monitoring may be warranted for premature infants who are at high risk of recurrent episodes of apnea, bradycardia, and hypoxemia after hospital discharge. The use of home cardiorespiratory monitoring in this population should be limited to approximately 43 weeks' postmenstrual age or after the cessation of extreme episodes, whichever comes last.
3. Home cardiorespiratory monitoring may be warranted for infants who are technology dependent (tracheostomy, continuous positive airway pressure), have unstable airways, have rare medical conditions affecting regulation of breathing, or have symptomatic chronic lung disease.
4. If home cardiorespiratory monitoring is prescribed, the monitor should be equipped with an event recorder.
5. Parents should be advised that home cardiorespiratory monitoring has not been proven to prevent sudden unexpected deaths in infants.
6. Pediatricians should continue to promote proven practices that decrease the risk of SIDS—supine sleep position, safe sleeping environments, and elimination of prenatal and postnatal exposure to tobacco smoke.

## Commentary Review—Bacterial Infections and SIDS

By Dr. Thomas G. Keens

June 5, 2008

This commentary written by Dr. Thomas G. Keens is in response to a research article, recently highlighted in the news, about bacterial infections in babies who died from SIDS. The reference is: Weber, M.A., J.J. Klein, J.C. Hartley, P.E. Lock, M. Malone, and N.J. Sebire. *Infection and sudden unexpected death in infancy: a systematic retrospective case review.* *Lancet*, 371:1848-1853, 2008.

The investigators reviewed bacterial cultures taken at autopsy from 470 babies who died suddenly in the U.K. The study had the advantage that all autopsies were performed by pediatric pathologies, and a standard autopsy protocol was used to determine the cause of death. Infants were subsequently divided into three groups: (1) Unexplained deaths. (2) Explained with histological evidence of infection (i.e., pneumonia, meningitis,

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etc. ), and (3) Explained by non-infectious causes (trauma, etc.). There was a high rate of finding positive bacterial cultures in all groups of babies, even those who died from non-infectious causes. The investigators further divided the bacterial results into three groups: (1) Those bacteria known not to be associated with disease (non-pathological). (2) Those bacteria associated with disease and/or death, with histological evidence of infection and (3) Those bacteria which could be associated with disease or death in the absence of obvious histological evidence. This latter type of bacteria may be the most important if one thinks that bacterial infection causes SIDS. For this latter type of bacteria, 24% of babies in the explained group due to infections had positive cultures. 19% of the babies in the unexplained category had positive cultures. But only 11% of those babies in the explained due to non-infectious causes group were positive. This was a statistically significant difference. The most common organisms cultured from this group were *Staphylococcus aureus* and *Escherichia coli*. Those babies with positive cultures tended to be older than those with negative cultures.

It is interesting to note that there is a relatively high incidence of positive bacterial cultures in all groups. However, the incidence is higher in those believed to have died from infect-

Continued on column 3

tion, and in the unexplained group. Even in the group thought to have died from infection, only 24% of babies grew positive cultures of the bacteria which we should most worry about. I do not think this article represents a "breakthrough", as was suggested by the media. Infections have been considered as possible causes or contributors to the cause of death in SIDS in fact for many years. There may well be some mechanisms of infections perturbing autonomic nervous system dysfunction, inflammatory reactions, or others, which remain to be elucidated, and which may ultimately prove to contribute to the cause of SIDS. However, I think it would be premature to suggest that SIDS is due to bacterial infection based on this study. Of course, the cause of SIDS is not known. Therefore, any research which sheds light on possible causes, mechanisms, or contributors should be encouraged. This study is no exception, but I don't think it can yet be considered to be the answer.

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## Newsletter

If you would like to contribute an article or poem to an upcoming issue of **Reflections**, please contact: Lisa Biakanja at (714) 960-9897 or email her at [lbiakanja@yahoo.com](mailto:lbiakanja@yahoo.com). **The next newsletter deadline is 7/1/09.** We encourage your participation!

## *A Thousand Ways to Grieve*

By Margaret Brownley Bereavement Magazine March/April 2000  
www.bereavementmag.com

*I'm an active griever. By active, I mean that during those first few months following my loss, I devoured every book on grief I could get my hands on. I poured out my agony in my writing, attended grief seminars, went through photo albums and I searched the Internet for helpful sites. I cried and fumed and spent long hours talking to anyone who would listen.*

*My husband simply withdrew and grieved in silence. Though we lived in the same house, grieved the same loss, and shared a life together, we were apart in our grief. We all have our own ideas on how to grieve and we're quick to judge those who don't conform to our way of thinking. When Prince Charles wore a blue suit to Princess Diana's funeral, he was condemned by the press until it was*

*Continued on column 2*

c

*learned it was his former wife's favorite.*

*A friend of mine was criticized for wearing a pair of red strap, high-heel shoes to her husband's funeral, the same shoes she wore on the day they met.*

*If we are to grieve in harmony with those around us, we must give up the notion that grief can be expressed in limited ways. I once thought that grief manifested itself only in tears and depression. But I've seen what others whose vision is greater than mine have accomplished in the name of grief. Candy Lightner, the founder of Mothers Against Drunk Drivers, is a good example.*

*Resolve to make peace with someone who grieves in ways that seem odd to you. Try expressing your grief in a new way: write a poem or song, start a journal, buy your loved one a gift and send it to someone you know who would love and appreciate the gesture. Wear something outlandish. Buy a bouquet of balloons in your loved one's favorite color. Laugh at something that would make your loved one laugh.*

*Tears, depression and sadness are all acceptable ways to show grief. So are blue suits and red shoes.*

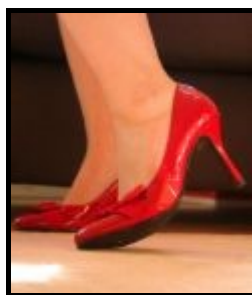
2. *Tell your friends to make a specific date with you; none of this "we must get together for lunch." Remind them that you're bound to have "down" times and their patience would be appreciated.*
3. *Tell them to please feel free to talk about the person that has died—and don't avoid that person's name.*
4. *It's important for friends to understand that you may appear to be "doing so well" but on the inside you still hurt. Grief is painful, it's tricky, and it's exhausting.*
5. *Ask your friends to care, but not to pity you.*
6. *Make plain that friends and relatives can still treat you as a person who is still in command and you can think for yourself.*
7. *Tell your friends that it's all right to express their caring. It's okay for them to cry; crying together is better than avoiding the pain.*
8. *Let your friends know, too, that it's all right to say nothing. A squeeze or a hug are often more important than words.*
9. *Let people know that they can invite you to socialize, but that you might decline.*
10. *Ask your friends to go for walks with you. You and your friends can "walk off" feelings. Walks promote conversation and help fight depression.*

*— by Ruth Jean Loewinsohn as printed in TCF Mt. Vernon, OH February, 1997 Newsletter*

## **REFLECTIONS**

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Editor: Lisa Biakanja

*Reflections* is a quarterly publication of the Guild for Infant Survival, Orange County—a non-profit organization. *Reflections* is committed to the collection and dissemination of accurate, up-to-date, scientific and lay information and the correction of misinformation related to SIDS. The Guild is dedicated to the support of families and friends suffering the death of an infant to SIDS.



### *Helping Others Help You— Ten Rules for Self-Healing*

1. *Tell friends to call you often. Explain that after the first couple of months you'll need their calls.*

*Continued on column 3*

**A Child Care Provider's Guide to Safe Sleep**

**provided by American Academy of Pediatrics**

Share this information with your child care provider.

**Create a Safe Sleep Policy**

Create and use a written safe sleep policy—reducing the Risk of Sudden Infant Death Syndrome, Applicable Standards from Caring for Our Children National Health and Safety Performance Standards. Guidelines for Out-of-Home Child Care Programs outlines safe sleep policy guidelines. Visit <http://nrc.uchsc.edu/SPINOFF/SIDS/SIDS.html> to download a free copy.

**A safe sleep policy should include the following:**

- ◆ Healthy babies should always sleep on their backs. Because babies sleeping on their sides are more likely to accidentally roll onto their stomach, the side position is not as safe as the back and is not recommended.
- ◆ Require a physician's note for non-back sleepers that explains why the baby should not use a back-sleeping position, how the child should be placed to sleep, and a time frame that the instructions are to be followed.
- ◆ Use safety-approved cribs and firm mattresses (cradles and bassinets may be used, but choose those

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that are JPMA (Juvenile Products Manufacturers Association) certified for safety.

- ◆ Keep cribs free of toys, stuffed animals, and extra bedding.
- ◆ If a blanket is used, place the child's feet to the foot of the crib and tuck in a light blanket along the sides and foot of the mattress. The blanket should not come up higher than the infant's chest. Sleep clothing, such as sleepers, sleep sacks, and wearable blankets, are good alternatives to blankets.
- ◆ Sleep only 1 baby per crib.
- ◆ Keep the room at a temperature that is comfortable for a lightly clothed adult.
- ◆ Do not use wedges or infant positioners, since there's no evidence that they reduce the risk of SIDS.
- ◆ Never allow smoking in a room where babies sleep, as exposure to smoke is linked to an increased risk of SIDS.
- ◆ Have supervised "tummy time" for babies who are awake. This will help babies strengthen their muscles and develop normally.
- ◆ Teach all staff, substitutes, and volunteers about safe sleep policies and practices and be sure to review these practices often.

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When a new baby is coming into the program, be sure to talk to the parents about your safe sleep policy and how their baby sleeps. If the baby sleeps in a way other than on her back, the child's parents or guardians need a note from the child's physician that explains how she should sleep, the medical reason for this position and a time frame for this position. This note should be kept on file and all staff, including substitutes and volunteers, should be informed of this special situation. It is also a good idea to put a sign on the baby's crib.

**If you are not sure of how to create a safe sleep policy, work with a child care health consultant to create a policy that fits your child care center or home.**



There is no more ridiculous custom than the one that makes you express sympathy once and for all on a given day to a person whose sorrows will endure as long as his life. Such grief, felt in such a way, is always "present". It is never too late to talk about it, never repetitious to mention it again.

Marcel Proust, from his "*Letters*" 1871-1922.



# Love Brings Hope and Life

by Sherokee Ilse, 2008

It begins with love

Wanting more, waiting for new life

Planning for a future forever changed with  
*Children.*

Then lightning strikes

Followed by a deep, lonely

*Darkness.*

Who could be prepared

For this type of anguish?

So alone, yet trying to be

*Together.*

Love pulls us through

Each day as we struggle to

*Survive.*

Head down, heart hurts,

Stress and confusion

Lead to arguments, silence, and

*Pain.*

Glimpses of beauty

And love eventually bring

*Hope.*

Life and time

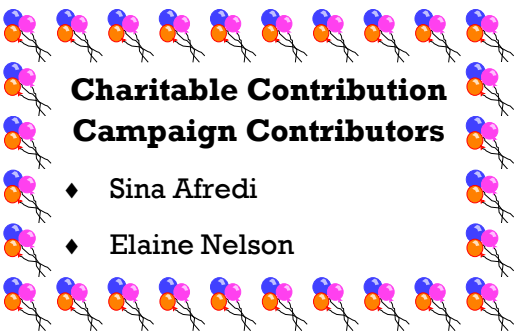
March on, while memories remain.

We are one; we will remember

Love reminds us to

*Live—*

Again.



**Charitable Contribution Campaign Contributors**

- ◆ Sina Afredi
- ◆ Elaine Nelson

But it Hurts Differently

There is no way to predict how you will feel. The reactions to grief are not like recipes with different ingredients and certain results. Each person mourns in a different way. You may cry hysterically or you may remain outwardly controlled, showing little emotion. You may lash out in anger against your family and friends, or you may express your gratitude for their concern and dedication. You may be calm one moment-- in turmoil the next. Reactions are varied and contradictory. Grief is universal. At the same time it is extremely personal. HEAL IN YOUR OWN WAY.

Rabbi Earl Groliman

L.L.F.\* TCF Orange County Chapter Newsletter November 2004



Upcoming Southern California Regional SIDS Council Meetings will be held from 10 am to 1 pm at the Southern California Edison building in Westminster. All parents are welcome to attend. Next meeting scheduled for

- ◆ May 14
- ◆ August 13

**There is Birth  
And there is Death.  
In between the two,  
is Time.  
No one knows how  
much time.  
The time between is  
a Gift.**



**2009 SIDS Conference**  
**Tuesday, October 20,**  
**in Sacramento by**  
**Capital Building**



*Are you interested in receiving your newsletter by email? If so, please send an email to [gisoc@att.net](mailto:gisoc@att.net) and advise Barbara Estep.*

To the California SIDS Community:

For your interest, I append my response to a question about the use of home infant apnea-bradycardia monitoring in subsequent siblings of SIDS victims. If you find this helpful, please distribute it as you see fit. Thank you so much for helping to improve SIDS services, education, and research in California.  
--- Dr. Thomas Keens

Like other things in medicine, infant home apnea-bradycardia monitoring was once thought to be a good idea. If a baby could die because she stops breathing during sleep, what better way to go than to place a device on the baby which will sound an alarm if she stops breathing for 20-seconds or if her heart rate falls below 60-80 beats/minute (depending on age)? Research by Al Steinschneider, Dorothy Kelly, and others suggested that some babies were found not breathing, but could be resuscitated, and that these babies were at risk to do this again. The term "near-miss SIDS" was used to describe these babies, because it was thought that they would have died from SIDS had they not fortuitously been found, revived, and "saved". Hence, the boom in home monitoring

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occurred beginning ~1980, and it continued well into the 1990's and even after 2000. However, the use of home monitoring was not ever based by any scientific studies to show if they could prevent SIDS. With respect to SIDS siblings, who were once thought to be at increased risk of dying from SIDS compared to the general population, more recent studies suggested that their risk of SIDS was the same as the general population, that is, it was not increased.

In the early 1980's, our group (and others) showed that babies could die even if they were being monitored. That is, monitoring did not prevent death in all patients. At around the same time, David Southall in the United Kingdom performed a large study showing that apnea, periodic breathing, and low heart rates did not predict babies who would subsequently die. Studies in the U.S. confirmed these results. Other studies showed that home monitoring had little impact on SIDS rates or the numbers of babies dying from SIDS. All of these findings started some researchers questioning whether home monitoring in fact did anything.

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In the 1990's, we were privileged to be part of the NIH funded multi-center study called the CHIME Study (Collaborative Home Infant Monitoring Evaluation). The study was designed to find out what actually happened to "high risk" babies who were placed on home monitors. A custom monitor was designed for this study and used to monitor over 1,000 babies for the first 4-6 months of life. A lot of information was derived from this study. However, the hypothesis of the study (that SIDS siblings, preterm infants, and infants with apparent life-threatening events [previously near-miss SIDS] were at increased risk of having significant cardiorespiratory events compared to control infants) was found to be false. Specifically, SIDS siblings, who were born at term, had no more apneas or bradycardias than healthy control infants. Further, the 20-second apneas, which sound alarms on conventional home monitors, were so common, even in healthy normal infants, that they were essentially of no significance, and certainly did not predict death. The CHIME study, in addition to other findings, turned the whole infant monitoring world upside down. Shortly after that, the

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American Academy of Pediatrics, based largely on the CHIME study results, did not recommend home monitoring, except for specific high risk groups (which does not include SIDS siblings; I append the papers to this e-mail).

The following recommendations are now made for subsequent siblings of SIDS victims:

1. Based on our current information, babies born into a family where a baby has previously died from SIDS are at about the same risk as the general population. This is currently approximately one-in-2,000 live births. Also, based on our current information, there is nothing you did or did not do which caused your baby to die. There is nothing you could have done to prevent your baby from dying. SIDS is a natural cause of death, although we still do not know how SIDS deaths occur.
2. During your pregnancy, do everything you can to have a healthy baby. Begin prenatal care early. Follow your obstetrician's advice. Do not smoke during pregnancy. Do not drink

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alcohol or take illicit substances (especially opioids or cocaine).

3. Once your baby is born, be sure to follow the "Back to Sleep" recommendations. These have been shown to decrease the number of babies dying from SIDS. Especially be sure to have your baby sleep on the back, use safe bedding, avoid cigarette smoke exposure, do not overheat your baby, and breastfeed if possible.
4. There is no testing that can be done which will predict whether or not a baby will die from SIDS. Therefore, performing sleep studies, ECGs, etc., are not helpful, and they will not predict whether or not your baby will die.
5. Find a pediatrician who is sensitive to the fact that you had a previous baby die from SIDS, and who will take your concerns seriously. The best test to identify health problems is a good history and physical examination by your pediatrician. It may be that his or her evaluation will suggest the need for some testing. Testing which is directed by a pediatric evaluation is more

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likely to be useful than the indiscriminate use of tests.

6. Home monitoring has not been shown scientifically to prevent SIDS recurrence in SIDS siblings.

The CHIME study suggests that asymptomatic siblings of SIDS victims have the same apneas as healthy control infants without a family history of SIDS. Home monitoring works by detecting an apnea or bradycardia, and alerting the caregiver, who must then respond and revive the baby if necessary. However, SIDS siblings do not have more apneas or bradycardias than normal infants. Therefore, it does not make sense to use home monitors to try to reduce the incidence of SIDS detected as apnea or bradycardia. We do not recommend the use of home monitors in SIDS siblings, as there is no evidence that it will prevent SIDS.

It has been suggested that SIDS parents may be sufficiently anxious about suddenly finding their subsequent baby dead that the use of a home monitor will reduce their anxiety and improve their parenting. There is no evidence that the use of

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## MEMORIAL DONATIONS

## Special Thanks

**Donations have been made in loving memory  
by those who loved them:**

**In Memory of Adam Brittain**

Andrew & Dorothy Clay

**In Memory of Jason Doo**

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Margaret & Iain McCormick

**In Memory of Jacob Tyler "Baby Jake"**

**Williams**

Steve, Mary, Zachary & Katie Williams

a monitor will reduce anxiety or improve parenting. In fact, there are many stresses caused by the use of home monitoring. If you are the caregiver of your baby alone, you can not do loud activities (such as vacuuming, taking a shower, playing loud music, etc.), which may prevent you from hearing a home monitor alarm. It is difficult to find baby sitters who are trained and skilled in infant cardiopulmonary resuscitation and the graded response to monitor alarms. Thus, parents are stressed with the continuous responsibility of caring for their

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This newsletter is being published thanks to a grant from the Pacific Life Foundation.

"high risk infant", often without respite. Therefore, home monitoring is not recommended for the purpose of reducing parental anxiety, as there is no evidence that monitors will do this.

If a family is interested in home monitoring despite the above, this should be discussed with your pediatrician. There are no guidelines for how long home monitoring should be used. If a home monitor is used, it has traditionally been recommended for the first 6-months of life, since 90% - 95% of SIDS occurs during that time. Most health insurance and MediCal or Medicaid will not pay for home monitoring of a SIDS sibling, because it is not a treatment for something actually wrong with the child. Therefore, families using home monitoring will usually have to pay for this out of pocket. However, its use is not recommended.

I hope this is helpful. If you have any comments or further questions, please do not hesitate to contact me. Thank you very much... Dr. Thomas Keens

# 2009/2010 MEETING CALENDAR

**Parent Support Meetings**– All meetings are from 6:00—7:30 PM  
Dinner will not be served;

**\* Please RSVP to the parent host prior to the meeting**

**November 8, 2009**  
**Sunday**  
Home of Jordy Jahn  
26702 Las Tunas Dr.  
Mission Viejo, CA 92692  
RSVP to (949) 347-8583

**December 13, 2009**  
**Sunday**  
Home of Rachel Strickland  
2828 East Puritan Place  
Anaheim, CA 92806  
RSVP to (714) 630-0400

**January 10, 2010**  
**Sunday**  
Home of Jordy Jahn  
26702 Las Tunas Dr.  
Mission Viejo, CA 92692  
RSVP to (949) 347-8583

**Business Meetings**– Business meetings are held at the home of Rachel Strickland located at 2828 East Puritan Place in Anaheim (714) 630-0400. Meetings begin at 7:00 PM. If you would like to have an item added to the agenda, please contact Rachel at the number referenced or email her at [shawnrachelhuntr@aol.com](mailto:shawnrachelhuntr@aol.com).

**January 20, 2010**

**April 14, 2010**



**GUILD FOR INFANT SURVIVAL, ORANGE COUNTY**  
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**IRVINE, CA 92623-7432**

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