



PLIDA Newsletter

Pregnancy Loss and Infant Death Alliance

Parent Support :: Advocacy :: Awareness :: Resources

Winter, 2009-2010

[One kind word can warm three winter months.](#) Japanese Proverb

*We are grateful for **you**, the PLIDA members, who work so hard at offering families your kind words and presence to warm them during their winter months of grief.*



We are thrilled that so many of you have contributed to this newsletter! It is full of great ideas and information~

Information on the next Perinatal Bereavement Conference

New Resources for you and your families

Ideas for events next October-Perinatal Bereavement Month

New ways you can connect with other members

And much, much, more.

Welcome!





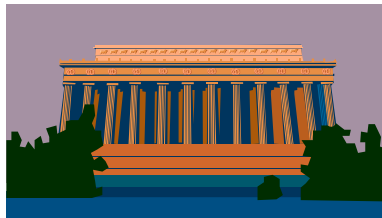
From the PLIDA Prez.....

Some updates to share from the desk of the President and Conference Committee Chair. Everyone is busy these days, but one of the exciting things keeping me most busy is working to plan the details of our 2010 Conference: ***The International Conference on Perinatal and Infant Death: Partnerships for Prevention, Advocacy, Research, and Support.***

We have the exciting opportunity to partner together with the Association of SIDS and Infant Mortality Programs (ASIP www.asip1.org) to bring an even wider range of speakers and topics...and incredible professionals...together for four days of learning, sharing, networking, and advancing knowledge in this area in which we are all dedicated.

Mark your calendars for November 4-7, 2010 in beautiful Alexandria, VA (a historical suburb of Washington, DC) at the Westin Alexandria. Keep watching your email...as well as PLIDA's Facebook page...for the latest information and announcements. Look for "Save the Date" to arrive in the coming months as we approach gathering together again.

If you haven't yet received the SAVE THE DATE email, please make sure you accept members@plida.org in your email system, so it doesn't automatically go to your junk mail.



Announcing the Next Conference!!

The International Conference on Perinatal and Infant Death: Partnerships for Prevention, Advocacy, Research and Support

**November 4-7, 2010
Alexandria, Virginia**

www.perinatalbereavementconference.org

“What I Did Last October”

Ideas for National Perinatal Bereavement Month

We asked for your stories of how you helped your families honor National Perinatal Bereavement Month and **YOU** responded!

Linda Heitger, RN, BA, the Perinatal Loss Coordinator from Mercy Medical Center in Canton, Ohio writes that they held their 5th Service of Remembrance for families who have had a perinatal loss. Their speaker was Patty Young who, along with her husband Cyle, has started the website www.peacebears.org. They also donated teddy bears that they have added a name Peace, to the foot and a necklace with their story.

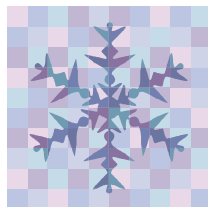
For the first 3 years the Ohio group had the service at a local church. Last year they changed the location to the chapel at the hospital. Linda states, “Both places have their good and bad issues.”

Pros for having the service on site at the hospital chapel include:

- nondenominational
- people are able to go back to the area where they had their baby
- better support from institution
- co-workers are less intimidated by being at a place they are comfortable with
- families know where the hospital is

Cons for having the service on site at the hospital chapel include:

- less support and awareness from the outside community thus not being able to educate people about perinatal loss
- families are coming back to an area that sometimes they don't want to come: brings up memories



“What We Did Last October”

Patti Walker Patti.Walker@albertahealthservices.ca of Alberta, Canada writes: We just completed our 2nd Annual Walk To Remember this past Sat - Oct 3. We had 751 registrants even though the weather was dark, dreary and cold (about +2 C, 36 F). Part of the Walk is a teddy bear drive - to collect NEW teddies that have been personalized by bereaved families to give to newly bereaved families in the hospital. Contact Patti to see examples of the creative and personal hand-outs they have developed for this event.



In early October, PLIDA Board Members, Tammy Ruiz & Lori Ives-Baine as well as PLIDA Member, Mary Peroutka hosted a Perinatal Hospice Retreat that had 10 participants for a weekend in the mountains to teach and learn in a collaborative format and atmosphere. We had a therapist, an MD, a Chaplain, a parent-advocate, and 6 nurses each with ties to the Perinatal Hospice model of care.



For Perinatal Bereavement month, the parents from my area - Fredericksburg, VA - held a "Healing Hearts Walk to Remember" and was attended by 150 people. There was a walk, Memorial Service, balloon release and fundraising for www.LLOST.org, a foundation that provides supplies to Perinatal Bereavement programs in the VA/DC area. This was a parent planned and run event and they provided much support for people not previously known to our support group who came to the walk to find kinship with other bereaved parents. Tammy Ruiz, RN

Requests for Information, Resources, etc...



We Want YOU! To help with the next conference! Have you ever wanted to volunteer with PLIDA but didn't know how or weren't able to make a long-term commitment? Contact us to join the conference planning committee! You could review applications for presentations, contact vendors, assist with conference planning, etc, etc, etc. Please contact info@plida.org if you can lend a hand!



Along that thought, start thinking NOW about submitting your own application to present a break-out session, a poster presentation or to be a vendor at the conference. Look for upcoming email blasts and check back often at www.perinatalbereavementconference.org for instructions and deadlines.

Beier, Pam (pbeier@saint-lukes.org) is looking for resources for bereaved grandparents and also your suggestions for sibling loss support.



Legislation and Advocacy Updates

Newly Introduced Legislation will Support Education and Prevention Efforts for Stillbirth, SIDS and other Sudden, Unexpected Infant Deaths (SUID)) [S1445, HR3212](#) (www.firstcandle.org)

First Candle has been influential in the introduction of Stillbirth and SUID Prevention, Education and Awareness Act of 2009 which was filed on July 14 by Senator Frank Lautenberg, D-NJ. A companion bill was filed in the House by Frank Pallone, Jr., D-NJ-6. This bill would improve the collection of critical data to determine the causes of stillbirth, SIDS and SUID, increase education and awareness about how to prevent these tragedies in the future and expand support services for families who have experienced a stillbirth, SIDS or SUID loss.

- Every year there are more than 25,000 stillbirths in the United States. For more than half these deaths there is no known cause, leaving parents with more questions than answers as to why the baby died. The bill would expand activities to identify the causes of stillbirth, identify ways to prevent it in the future and increase education and awareness about the issue among healthcare providers and parents. US citizens are encouraged to contact their House and Senate members as soon as possible to help by seeking cosponsorship, which will help it pass more quickly through a LETTER-WRITING CAMPAIGN. To help:
- Visit www.house.gov to get contact information for the Congressman in your District. You will need your 9-digit zip code. If you do not know your 4 digit extension, you can get it at <http://zip4.usps.com/zip4/welcome.jsp>. You will then be able link directly to you Representative's website.
- Visit www.senate.gov to get contact information for your state's senators.

PLIDA Board Members



In our last newsletter we introduced you to the new executive board. Now meet some other members of the board!



Deborah L. Davis, PhD, is a developmental psychologist and author of several books, including *Empty Cradle, Broken Heart* (Fulcrum, 1996); *Loving & Letting Go* (Centering, 2002); and *Parenting Your Premature Baby and Child* (with Mara Tesler Stein, Psy.D.; Fulcrum, 2004.) Her next book, *A Gift of Time* (with Amy Kuebelbeck; Johns Hopkins University Press, 2010) supports parents who want to pursue perinatal hospice (www.perinatalhospice.org.) She is proud to be a founding Board member of PLIDA, and the primary author of its Position Statements and Practice Guidelines. It is an honor to be involved in such a visionary organization! Debbie can be reached at dmekdavis@yahoo.com.



Tammy Ruiz is a veteran of 24 years of nursing practice, most of it in the trenches of weekend nightshifts. A 1985 graduate of the Union Memorial Hospital School of Nursing, she married a Military officer who dragged her kicking and screaming across the country 7 times. During the orientations at her 14 different jobs, it took a while before she could see that the varied challenges and settings would eventually weave themselves into a rich tapestry of experience. These included Pediatric ICU, Home care, Hospice, Newborn nursery, but mostly NICU.

In addition to her nursing education and practice, she has studied Hospital Chaplaincy and has 2 units of Clinical Pastoral Education. In 2004 she took over the Perinatal Bereavement Program at Mary Washington Hospital as the only Perinatal Bereavement Coordinator in the Rappahannock area of Virginia and cares for women and families across the continuum from early loss to SIDS. She developed and implemented the "Garden of Angels" burial program to provide respectful burial for any death that occurs prior to birth - the program has thusfar buried 230 babies. Her "Perinatal Support Service" program is on of a very few Perinatal Hospice programs in Virginia. She has been featured in Nurse Zone, appeared on EWTN cable network and speaks on Perinatal Death issues in the DC area and at national conferences.



Joann O'Leary has a PhD in Work, Community and Family Education, a Masters in Maternal-Child Health from the University of MN and a Masters in Psychology through research from Queens University in Belfast, Northern Ireland where she was a Rotary Scholar. She has a background in nursing, preschool special education, a Parent-Infant Specialist in a high risk perinatal center and is an Infant Mental Health mentor for the state of MN. She is a consultant in the area of prenatal parenting and teaches for the Center for Early Education and Development at the University of MN. Her research includes the pregnancy following perinatal loss, raising children after a loss, and the adult child born after an infant loss.

She has published over 28 articles focusing on prenatal parenting, how infant loss changes the experience of the pregnancy that follows and impacts family members. She has developed a guided imagery CD on the Parenting experience of pregnancy and produced two videos and a booklet on pregnancy following perinatal loss. In 2005 she was awarded the Lamaze International Marjorie Karmel Award for her work with families pregnant after loss.



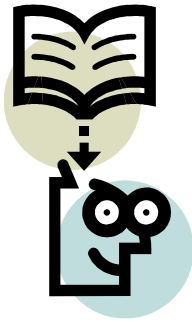
Patricia Wright is a registered nurse and has practiced in medical-surgical and hospice nursing. She also has experience as a childbirth educator and prenatal fitness instructor. She currently teaches nursing at The University of Scranton, and recently completed a doctoral dissertation on maternal perinatal bereavement. (Congratulations, Trish- it was lots of hard work and will be a valuable resource- PLIDA will be asking for you to write a piece about your dissertation in a future issue of our Newsletter!!!)

Resources and News to Share

These resources were compiled by **PLIDA** to promote awareness, advocacy, support, and education. Views and opinions contained in these resources do not necessarily reflect those of PLIDA, its Board of Directors, members, or employees. In the interest of inclusiveness and sensitivity to diversity, resources that propound any particular religion are not included.

Being listed as a resource herein does not constitute or imply endorsement, recommendation, or favoring by PLIDA, and shall not be used for advertising or product endorsement purposes.

Check out the entire PLIDA resource list at www.plida.org/resources



Grieving in the NICU: Mending Broken Hearts When a Baby Dies, an insightful video that offers guidance for grieving families following the death of a baby, was a finalist for the 2009 International Health & Medical Media Award (FREDDIE Award) for best coping production. Due to the collaborative efforts of DIA Productions and Share Pregnancy & Infant Loss Support, this 90-minute video is a thoughtful resource for professionals and a source of validation and healing for bereaved families. Contact: Megan Nichols, National Share Office, 636-947-6164, mnichols@nationalshare.org



SHARE's newsletter is bereaved parent based is now totally updated, free and online www.nationalshare.org/newsletter/html.



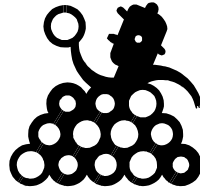
PLIDA is hitting the big times! Thanks to PLIDA member Suzanne Helzer, the fifth edition of the classic *Manual of High Risk Pregnancy and Delivery* will include PLIDA's Practice Guidelines "When Parents Want to Hold Their Baby" and "Offering the Baby to Bereaved Parents." (The book's publisher Mosby/Elsevier has been granted formal permission by PLIDA.)



In addition, Suzanne teamed up with PLIDA Board Member, Debbie Davis, who

completely overhauled the chapter on perinatal grief. It's now titled "Perinatal Death and Bereavement Care." Along with PLIDA's Practice Guidelines, it now includes a history of bereavement care; the parent's experience of grief, adjustment, and spending time with their baby; the importance of supporting parents through the subsequent pregnancy; and summaries of three cutting-edge topics: perinatal hospice, palliative care, and parents providing their baby's after-death care in the home.

The book's venerable author, **Elizabeth S. Gilbert**, RNC, MS, FNP-bc, CNS, is pleased as punch with this updated chapter, and our hats off to her for helping us promote PLIDA's work. We will keep you posted about its publication date!



Laura Stutzman laura-stuzman@smh.com of Sarasota Memorial Hospital writes: Take care of your donors and sewing ladies! We all get behind on thank you notes but I am usually forgiven because every year during Volunteer Appreciation Week (April) I mail them something to recognize their generosity. One year I made certificates on the computer, another I made blue ribbons ("you deserve a blue ribbon!"), last year I made bookmarks with "Your love shows in everything you make...In every stitch you take...Thank you from (my program, hospital and year), four to a page and laminated, cut with the paper cutter, hole punched on top with a narrow ribbon through it. The project takes minimal time and I promise you will get calls and more donations.



KICKS Counts Initiatives

Approximately 80% of women who had a stillbirth describe having noticed decreased movement shortly before their baby died. (Note: Many other moms have noted decreased movement yet their babies lived). There is a shared goal in some countries and regions to see if 'movement awareness' will ultimately save babies lives. Moms are encouraged to monitor movement, call their doctors if change occurs, go in to be checked, and if appropriate-their medical caregivers will intervene to save the baby.

To that end, First Candle (www.firstcande.org), with a grant from the Heinz Family Philanthropies, has initiated a new US initiative – **KICKS count!** They have also joined forces with Finger Lakes Productions International to secure celebrity spokespersons and produce high quality radio public service announcements (PSAs) to deliver important information to expectant parents on counting baby's movement. Their campaign literature begins with:

Their message is: *Counting your baby's kicks during your last trimester is a simple, free and effective way to help monitor your baby's health. Many experts now agree that it may also help reduce the risk of stillbirth.*

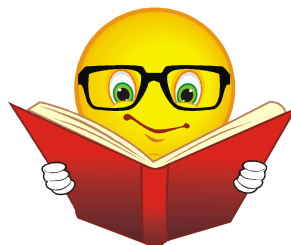


Thousands of Kick Counts brochures have been made available to doctors, midwives, and parents who wish to better understand this method of counting movement toward the end of pregnancy with the goal of hopefully reducing stillbirth.

The guidelines suggest that paying attention to movement since, “What your baby is telling you with its kicks (movements) is important!” and it goes on to say, that there are reasons to call your doctor immediately... “If your baby kicks less and less in the course of a day, or you don’t feel any kicks on any given day...” The brochure suggests that “...kick counting is being recognized as the first proactive strategy that may reduce the risk of stillbirth.” For more information on this initiative, to download a brochure or a Kicks Count chart (a tool to help keep track of the movement), visit www.firstcandle.org/kickcounts



An Iowa nonprofit, Healthy Birth Day, has a statewide Count the Kicks campaign also. They encourage people to visit www.countthekicks.org to learn more.



Judy Cohen writes: I am an RN who has recently written a small booklet for pregnant women called "Having a Baby: A Nurse's tips on childbirth preparation". I also have information on my web site on coping with pregnancy loss. Please check out my site www.GetReady4Baby.com

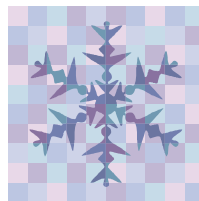


Joann O'Leary recently attended the International Pre and Perinatal Psychology Conference in Heidelberg where she spoke on Raising Children after a Loss. The universal need to acknowledge how infant loss changes family dynamics is powerful to see. Many participants shared their personal stories. Joann hopes to see many professionals from Germany at our next conference in DC in 2010!

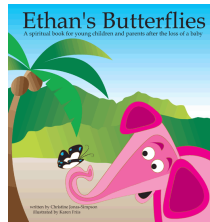
Couple Communication After a Baby Dies: Differing Perspectives, Sherokee Ilse and Tim Nelson



Couple Communication is sensitively written and addresses the common and not so common issues men and women face for a long time. Brain differences are presented, personality and gender discussions ensue, and the stories of both couples (Nelsons and Ilse) are shared along with other couples' experiences, and practical suggestions are offered. The last few pages can be used as worksheets in support group, by counselors, or by families in the privacy of their own home. (If you wish to download a picture, you can take it from the online store part of the website www.babiesremembered.org or from the #3 newsletter at the same site (top of home page).



Precious Lives – Global Collaboration in Stillbirth and Infant Death, International Conference, Sydney, Australia, October 8-10, 2010, Co-sponsored by Int'l Stillbirth Alliance (ISA) and Int'l Society for the Study and Prevention of Infant Death (ISPID). www.isaispid2010.com



Announcing the Second Edition of Ethan's Butterflies: A spiritual book for young children and their parents after the loss of a baby.

Comments about the book:

Sometimes a book comes along that has heart and soul. Such is *Ethan's Butterflies*, a book to share with children when a baby sibling dies. The book centers on a family of elephants, appropriately chosen because elephants have complex and nuanced mourning rituals. Big sister Emma, the book's storyteller, and big brother Edgar share with us the experience of their baby brother's death. These elephant siblings cry, get mad, wonder what they did to cause Ethan's death. They struggle with the question, *What happens after death?*, much like we adults do. Perhaps that is the true beauty of this book, written for children, but illuminating the path of grieving for big people, too.

Rana Limbo, PhD, RN, PMHCNS-BC
Director of Bereavement and Advance Care Planning Services,
Gundersen Lutheran Medical Foundation, Inc.
Faculty Associate, University of Wisconsin-Madison School of Nursing

Christine Jonas-Simpson has produced a much needed book for young preschool children on the loss of a baby. *Ethan's Butterflies* is written at a level that is understandable with enough information for parents to individualize and adapt for their family. The book validates the confusing feelings children experience when loss becomes part of their family story. The book is written in a way that allows parents to modify the spiritual message to fit with their own beliefs about life after death. This book also reinforces that a sibling relationship lasts forever. A much needed resource for bereaved parents who have young children at home.

Joann O'Leary, PhD
Parent-Infant Specialist
Centre for Early Education and Development
University of Minnesota
jmbirthconsultants.com

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Babies Remembered Newsletter, launched in May, is a new service for care providers and families full of rich resources, suggestions, and tips. The first three comprehensive newsletters are free to view on the home page of the website – www.babiesremembered.org. The website, soon to have a complete facelift, has many project announcements, practical information, books, videos, and resources, reciprocal links, a place to honor babies, and so

much more. It can also be reached presently at www.wintergreenpress.com. PLIDA members are invited to submit items, links, resources, etc. to both the newsletter and the website.



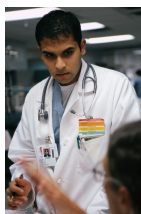
New Translation Resource

I am Here and I Care—a resource to help staff ‘connect’ with families and offer sensitive care while waiting for translation staff or volunteers to come.

This 3 ring binder (created by request from frustrated hospital nurses at the Cincinnati PLIDA conference) has 100 yes/no questions and comments for bereaved families who have not yet met a translator. It is also good to use before hooking them into the telephone translation services. The care provider can choose the language, then point to questions and comments in English written in their language. Some of the questions/comments are: "My name is _____." "I have called for a translator. Do you need anything?" or "Are you in pain?" or "Do you have someone you need to call?" or "Do you want to see your family?" or "I am so sorry your baby has died. We are here to help you."

The languages so far are: Spanish, Hmong, Russian, French, Somali, and Chinese. Are there other languages you need or can help with? Contact us at info@babiesremembered.org.

Cost: \$150 which entitles the facility to make as many copies as needed for the facility (not to be shared with other sister hospitals. A discount will be offered for extra copies for other facilities within the organization.) Order at online store - www.wintergreenpress.com



Help for Physicians by a Physician

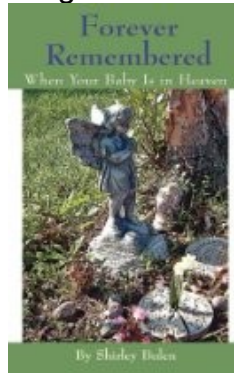
Dr. Michael Berman recently wrote a CME document for physicians entitled: ***Find the right words after a pregnancy loss***, Contemporary OB/GYN, March 2009. Practical and personal, it's a must read for every physician who cares for bereaved mothers. As a Clinical Professor of Ob-Gyn, and the founder-president of Hygei Foundation, Inc. and Inst. for Perinatal Loss and Bereavement, www.hygeiafoundation.org, Dr. Berman is a leader and amazing physician.



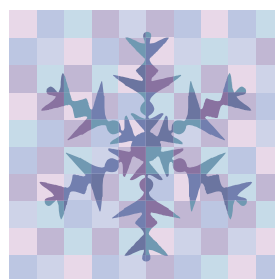
New LinkedIn Group announced – Perinatal/Neonatal Community Leaders Group. This group is for authors, parent advocate leaders, and care providers who lead programs in their facility or community. It is a free professional network (www.linkedin.com). This group offers a chance to link up, share tips and resources, ask questions of many at one time instantly, and so much more. If you wish to join, sign up for LinkedIn and then seek out the group by name. It's easy to join, meet friends, and network on this special topic.

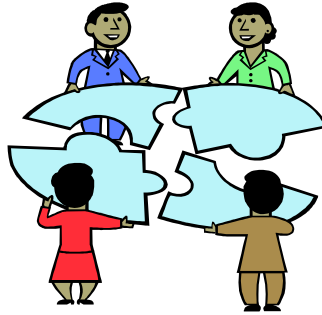


Shirley Bulen shirley.bulen@yahoo.com recently published a book. It is Christian focused to help families find comfort in relationship with God. "Forever Remembered: When Your Baby is in Heaven" is available through Amazon and most major book stores.



Todd Hochberg todd@toddhochberg.com of Touching Souls Bereavement Photography writes: This past April I was invited to exhibit my bereavement photographs at the Northwestern University Feinberg School of Medicine Medical Humanities & Bioethics Program. You may have seen the show. It was set in a beautiful, intimate space for the humanities library called Dollie's Corner - named for a respected Chicago Philanthropist. The exhibit was well received by the Medical School community as well as by folks outside the University including many bereaved parents and caregivers. Reaching medical school students early in their training is valuable in helping to foster greater support for families struggling with very sick and dying children and babies. To see a slideshow of the images from the exhibition go to www.toddhochberg.com/seeexhibitslides.html





Don't forget to stay connected to PLIDA and each other!!!
"friend" us on facebook or join the Yahoo group, check out all the
great resources at www.plida.org