



# PLIDA Newsletter

*Pregnancy Loss and Infant Death Alliance*

Parent Support :: Advocacy :: Awareness :: Resources **Fall 2008**

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## **Reflections on our National Perinatal Bereavement Conference, NPBC 2008**

**By Sarah Kye Price**

Some of us were revitalized by the speakers; some were reacquainted with old friends and colleagues; some made new connections with people close by or far away; some enjoyed the peace of the beach, the spa, or the pool. Some of us gave presentations; some volunteered; some shared their thoughts and stories; some bought an auction item; some propelled us to think about new directions for PLIDA; some volunteered for a committee or a Board position. Whatever you did...one thing or many...we all enjoyed the time spent together in Clearwater during NPBC 2008.

Many of us came back from NPBC with stories to share with our family, friends, and colleagues. I came back full of stories and wonderful memories of connecting with you all. But, I also came back professionally recharged and ready to take the steps forward that I could to support the caregivers who give so much to families in a time of loss. And, I was renewed in my own professional contribution to conducting research that informs and empowers social work professionals to openly discuss perinatal and infant death with all women, and particularly women and communities where there are disproportionately high rates of fetal and infant mortality.

I am reminded that one of the reasons it is so important and meaningful to attend NPBC is the amount of energy we receive when in the company of people who share mission, goals, and commitment to helping. It was recharging for me to be in the midst of all of you, and I am deeply grateful to be a part of such an amazing group of people in this season of giving thanks, celebrating family, and looking forward to a new year.



## **Notes from the PLIDA President**

by Beth Seyda, PLIDA Board President  
beth.seyda@plida.org

It's a chilly 25° here in NC right now, so I am closing my eyes and transporting myself back to mid-October at NPBC. Florida, sun, palm trees, swimming pool, sandy Gulf beach – ahhhh, much better. I recall singing & dancing while stuffing conference tote bags, enjoying a glass of wine with my fellow board members, meeting our keynote/concurrent/posters presenters and vendors, having dinner with a wonderful group of first time conference attendees, tears at the Celebration of Remembrance, feeling peaceful at the early morning outdoor Spiritual Healing, and hearing ideas from members at our PLIDA meeting. The warmth came not only from the beautiful sunny skies, but from all who attended the conference and their caring, sharing, interacting, and creating. Thank you to everyone for helping make the 2008 NPBC a success.

Switching gears a bit, I've been thinking about hope lately. We heard about hope during our presidential election. I recently attended a pediatric hospice conference and participated in a session on hope. I just read an article in a sports magazine where a coach said "I deal in dreams and hopes. Expectations come from other people who haven't invested anything in it". And that is when a light bulb went off for me, why there might be struggles with families over hope. Families are the ones who are 100% invested, perhaps hoping that their premature baby will live or hoping they can heal after a loss. Families often have hope as a guiding principle in their decision making and daily living. Hope sustains. I ask that all of you please hold hope and walk with families as they face changes with their hope.

*Hope has its own energy, and it will warm that ache out of you heart  
and pick up your spirits. Feel the energy of hope, cherish it in your  
mind, and use it as a tool on your path through life.*

-- Terry Lynn Taylor and Mary Beth Crain

I wish everyone happy and healthy holidays. I am hopeful for what 2009 brings!

-- Beth

## **Member Questions and Connections: Building our Connections via the Web!**

At our PLIDA membership meeting, many of you were craving for connections between members to share ideas and practices. We are listening and responding. A series of PLIDA connection pages will be in place over the next few weeks. But, several members or people requesting information already have questions to post to their colleagues and we don't want them to wait! Until our message boards are up and running, here are a few questions in search of responses.

Parent Speaker Desired around Neonatal Palliative Care: Sutter Sacramento/ Sierra Region hospitals are starting a Neonatal Palliative Care program at Sutter Memorial Hospital in Sacramento. Over 150 of our SCN nursing staff have received initial education/introduction into Palliative Care for the Neonate and in 2009 our goal is to provide additional education and training for the nursing staff in the domains of Palliative Care. Our SCN Palliative Care committee was wondering if you had any parent speakers who would be willing to participate in the education programs - speak to their own experiences and address what was helpful and what was not helpful. Request Submitted by: Bernadette Damper R.N. Palliative Care Nurse Coordinator ([DamperB@sutterhealth.org](mailto:DamperB@sutterhealth.org))

Program Evaluation and Assessment Tools Wanted: Hello! I am trying to find valuable and reliable surveys and assessment tools to use in evaluating performance improvement after implementing a perinatal bereavement program. Do you have any suggestions? Thank you, Carli Broyles ([Carli.Broyles@CHW.edu](mailto:Carli.Broyles@CHW.edu))

Support Group Survey Participation Sought: From Sherokee Ilse

I have noticed over the past 3-5 years or so that a number of support groups have been closing down (of course, a few new ones also started up). Even in my home area of Minneapolis - there used to be almost twice as many groups and now people have to travel quite far sometimes to attend one. I've wondered if we are seeing an overall decrease. Also, as I speak with facilitators I sense a frustration where they worry that attendance is going down and they don't know how to help keep it up. Meanwhile, I know of groups whose attendance is still up and they are willing to share how they 'work' it to keep those numbers up.

As a result, I have decided to conduct a short survey of groups and learn what techniques, tips, and ideas the leaders use to keep their attendance up, even in this age of internet. The internet offers a wonderful private service to families, which is especially helpful for the middle of the night and 'off' times when parents really need to chat...or for those who just prefer to be at their computer as they seek support. But websites and chat rooms do not totally take the place of sitting in a room with other moms and dads sharing and learning together. Both are important.

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To this end, I am asking for your assistance. If you help facilitate a group please take this short survey. Also, if you know of any groups, please forward this email group leaders. This will help in a few ways.

1. We'll access what is happening with support groups around the country (and world?)
2. We'll be able to expand our list of support groups with contact names (I'll share what I learn if you want to have the info.)
3. Once we have the data, we'll report back what we learn in hopes that it will help those running groups or considering starting a group.

The link to take the 10 question survey is below. This can be pasted onto a website for visitors to take or you can click on it and take it yourself.

[http://www.surveymonkey.com/s.aspx?sm=ei6D2p7mN2\\_2bm9TK3lezHaw\\_3d\\_3d](http://www.surveymonkey.com/s.aspx?sm=ei6D2p7mN2_2bm9TK3lezHaw_3d_3d)

Thank you for your assistance with this project. Please share this with any other groups you can think of.

Sherokee Ilse

[www.wintergreenpress.com](http://www.wintergreenpress.com)

952-476-1303

*Please post any questions or ideas for topical areas you'd like to see included on our message boards to [sarah.kyeprice@plida.org](mailto:sarah.kyeprice@plida.org) and I will happily integrate your requests. Look for emails in the next several weeks about where, when, and how to post these questions and responses as we strive to connect our members around the country and the globe.*



## **PLIDA Mission Statement**

As a nationwide, collective community, the Pregnancy Loss and Infant Death Alliance (**PLIDA**) works to ensure that all families experiencing the death of a baby during pregnancy, birth, or infancy will receive comprehensive and compassionate care from diagnosis through the reproductive years. Through collaboration between professionals and bereaved parents, we recommend and endorse standards of care and informed public policy, provide a clearinghouse for information and resources, recommend professional competencies, and promote increased awareness and research.

## Members in the Spotlight

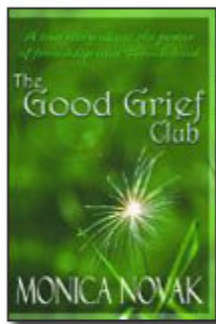
**On the Air:** PLIDA members Monica Novak and Beth Seyda were featured guests on Voice America Health and Wellness. Here is the announcement and a link to the archived show.

[www.voiceamericapd.com/health/010157/horsley103008.mp3](http://www.voiceamericapd.com/health/010157/horsley103008.mp3)

### HEALING THE GRIEVING HEART with Drs. Gloria & Heidi Horsley



THURSDAY OCTOBER 30TH 2008 AT 9AM PACIFIC (12PM EASTERN)



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[www.Health.Voiceamerica.com](http://www.Health.Voiceamerica.com)

Questions? Comments?

Call: 1-866-472-5792

### Miscarriage and Infant Loss

**Monica Novak** became a bereaved mother in 1995 with the stillbirth of her daughter Miranda. Monica's mission has been to bring comfort to bereaved parents and to promote awareness to the physicians, nurses, clergy, counselors, family and friends. She is the author of *The Good Grief Club*.

**Beth Seyda's** life was transformed in 1997 with the death of her newborn son, Dylan. She is Executive Director of Compassionate Passages, researcher, author, and co-producer of the award-winning educational film *When a Child Is Dying* and the accompanying *Supportive Care Handbook*.

Missed the Live Show? This episode rebroadcast at 9pm Pacific (12am Eastern)  
Past Episodes are available On Demand and Podcast Ready

For More Information on Dr. Horsley  
or grieving support services Visit:

[www.TheGriefBlog.com](http://www.TheGriefBlog.com)



## **A video of one family's journey during a Walk to Remember is shared via U-Tube**

**--Shared by parent, Beverly Johnson and PLIDA member Bobbi Gray**

*Avon, Indiana's annual Walk to Remember, sponsored by Hendricks Regional Health, was held on October 4, 2008. The Walk to Remember provides the community an opportunity to come together in remembrance of all the children that have gone before them. It gives grieving parents and families the chance to feel connected to others that truly understand their loss and the emotions that go with it. Before the program parents and family members had the chance to create a personalized ribbon in memory of their child/children. During the program the names of all the children that were represented were called allowing others to recognize their lives and their ribbons were added to a memory wreath. The program was followed by a bubble ceremony and a dove release representing the love sent forth to the children that are no longer with us. The program ended with a silent walk giving everyone the chance to reflect on the lives that have changed who we are and the footprints they left on our hearts.*



## **Legislative Updates and Advocacy:**

Trisomy 18 Act Passed: After three years of advocacy, the U.S. Senate and the U.S. House of Representatives passed S. 1810, the Prenatally and Postnatally Diagnosis Conditions Awareness Act, during the last week before Congress adjourned.

The Trisomy 18 Foundation applauds the final passage of the Pre-natally and Post-natally Diagnosed Conditions Awareness Act (S. 1810). The Act, now heading to the President's desk for signature into law, ensures that families who receive prenatal diagnoses of Trisomy 18, Trisomy 13, Down Syndrome or other genetic conditions will have access to up-to-date information about the nature of the condition and connection with support services and networks that could offer assistance.

To Read Press Release from the Foundation:

[http://www.trisomy18.org/site/DocServer/Microsoft\\_Word\\_-\\_Press\\_Release\\_for\\_S1810\\_Passage\\_Sept\\_25.pdf?docID=1021](http://www.trisomy18.org/site/DocServer/Microsoft_Word_-_Press_Release_for_S1810_Passage_Sept_25.pdf?docID=1021)

Also see Press Release from National Down Syndrome Society and National Down Syndrome Congress at:

[http://www.ndss.org/images/stories/NDSSresources/pdfs/kb\\_press\\_release.doc](http://www.ndss.org/images/stories/NDSSresources/pdfs/kb_press_release.doc)

### **Seeking Names of Supporters for Stillbirth and Stillbirth Research:**

Sherokee Ilse sends this request for support and help if you have program for miscarriage, stillbirth and neonatal death.

First Candle has been working with the House and Senate in DC trying to get some legislation passed that promotes stillbirth registries, research, and education/awareness. Senator Obama was moving it forward last spring. Now with his election win, his office passed it on to Sen. Lautenberg's of NJ.

Marian Sokol of First Candle is meeting with the Senator's staff and has been asked to give a list of organizations that support the issue of stillbirth and stillbirth research and who might be willing to advocate for it and enlighten members who could also help. You do not make a commitment by being on the list, but at least if you think your organization/group *might* be interested it would be helpful.

Do you want your organization/group to be on the list? And do you have any recommendation of others we should contact? They can be national or regional. Thank you for considering this. If you do agree to add your name, the Senator's office will need your organization's name, email address, a contact name, and phone number. Please provide this information to Marian [marian.sokol@firstcandle.org](mailto:marian.sokol@firstcandle.org)

## Research Updates

Joanne Cacciatore, Executive Director of the MISS Foundation, shared these recently released research publications which may be helpful for many of our members to read.

### **Effects of Contact with Stillborn Babies on Maternal Anxiety and Depression**

Authors: Joanne Cacciatore, Ingela Rådestad, J. Frederik Frøen

Journal: *Birth: Issues in Perinatal Care*, Dec 2008, Vol. 35 Issue 4, pp. 313-320

Some guidelines encourage mothers to see and hold their babies after stillbirth, which might be traumatizing. The study objective was to investigate the effects of women seeing and holding their stillborn baby on the risk of anxiety and depression in a subsequent pregnancy and in the long term. Methods: Thirty-seven organizations recruited women who had experienced stillbirth (N = 2,292 of whom 286 reported being pregnant). Anxiety and depressive symptoms were assessed by using the 25-item Hopkins Symptom Check List. Results: Among nonpregnant women, seeing and holding their stillborn baby were associated with lower anxiety symptoms (OR 0.68, 95% CI 0.49–0.95) and a tendency toward fewer symptoms of depression (OR 0.72, 95% CI 0.51–1.02), compared with pregnant women. Participants who were pregnant also had less depressive symptomatology (OR 0.57, 95% CI 0.43–0.75), but more symptoms of anxiety if they had seen and held their baby (OR 3.79, 95% CI 1.42–10.1).

Conclusions: Seeing and holding the baby are associated with fewer anxiety and depressive symptoms among mothers of stillborn babies than not doing so, although this beneficial effect may be temporarily reversed during a subsequent pregnancy.

### **The Impact of Circumstances Surrounding the Death of a Child on Parents' Grief**

Authors: LEONIEK WIJNGAARDS-DE MEIJ, MARGARET STROEBE,  
WOLFGANG STROEBE, HENK SCHUT, and JAN VAN DEN BOUT

Journal: *Death Studies*, 32: 237–252, 2008

A longitudinal study was conducted among bereaved parents to examine the relationship between the circumstances surrounding the death of their child and psychological adjustment. Two hundred nineteen couples participated at 6, 13, and 20 months post-loss. Examination was made of two categories of factors: those that were determined by the particular death circumstances (e.g., whether the parent was present at the death) versus those over which parents themselves could have influence (e.g., choice of cremation or burial). Results indicated that some but not all factors were related to adjustment over time. Importantly, the feeling of having said goodbye to the child and presenting the body for viewing at home were associated with lower levels of the parents' grief. Implications for supporting bereaved parents are discussed.

## PLIDA Member Awards

In October, PLIDA was pleased to honor our first PLIDA Member Awards recipients at the National Perinatal Bereavement Conference. These award winners were nominated by their peers for their commitment to PLIDA's mission in categories of: Support, Advocacy, Awareness, and Education. Each recipient will receive a complimentary membership renewal to PLIDA.

### Support: LeAnn Phelps

LeAnn was nominated by her colleagues and families that she has worked with in two hospitals for her dedicated compassion and support to families who have experienced perinatal and infant death. Her compassionate support work has impacted individuals, her health care community, and her community at large through her efforts. The letters of nomination on LeAnn's behalf convey sensitivity, dedication to supporting families as well as dedication to family support through the implementation of new support programs in her workplace. We honor LeAnn as exemplifying the qualities of Support that are part of PLIDA's mission.

### Advocacy: Laurie Van Damme

In Laurie's nomination, members describe her work as starting with a passion for helping families, but expanding beyond her job to truly educate the public about perinatal loss. She raises awareness about perinatal loss issues within her hospital through inter-disciplinary trainings as well as the creation of a remembrance garden. In addition she expands awareness to the local community through remembrance services, teaching students, and educating others such as the co-workers of a former patient who experienced perinatal loss. Most significantly, she has started using photography and remembrance videos to both preserve memories and advocate for parents by honoring their desire to create and maintain lasting memories and relationships.

### Education: Debbie Davis

Debbie Davis' nomination letter writes, "In any bereavement support program we depend on good information for ourselves and the families we serve. Debbie's books including *Empty Cradle*, *Broken Heart* immediately acknowledged parents' realities as well as providing sensitively written, relevant information." Debbie is very dedicated to accurate, useful information that support professional service delivery and advocates for the needs of bereaved parents. Her contributions to education also include authorship of the comprehensive position statements and practice guidelines available on PLIDA's website, showing her collaboration with professionals across professions, organizations, and countries to promote the education of health providers.

(Continued on the next page)

### **Spirit of PLIDA: Alana Roush**

Alana's nominators state that it is her indomitable spirit that inspires all who know her. In fact, we believe it is Alana's personal and professional experiences that have gone above and beyond to exemplify the Spirit of PLIDA. Alana's service history includes professional work with Bereavement Services/RTS as well as her work in perinatal grief support at several hospitals. She was chairperson of the 2000 NPBC conference and has been part of PLIDA since its first conceptualization. Her wisdom, insight, humor, and compassion make her an exemplary leader, teacher, advocate, and service provider. Even as her own health challenges have become increasingly severe in recent years, Alana has continued to maintain her committed involvement with PLIDA. Indeed, she is the Spirit of PLIDA in all that she has done and continues to do in support of PLIDA's mission.

### **The Dr. Joseph E. Graham & Family Outstanding Physician Award**

This award was established in 2005 at the suggestion of the PLIDA board after hearing a touching story regarding Dr. & Mrs. Graham's first child, Michael, who was born still. Dr. Graham and his wife Dorothea (Parks) dedicated their lives to helping mothers not only to have safe births, but to helping in times of adoption needs. Their home often became a haven while adoptive parents were cleared for adoption of a young mother's child who was not able to care for him/her.

Dr. Graham an obstetrician/gynecologist and surgeon, dedicated over 50 years to the practice of medicine. He entered the specialty of Obstetrics after 15 years as a flight surgeon during WWII and in general practice at home. 1954 was the first year medicine recognized the specialty practice of OB/GYN, and Dr. Graham was a charter member of the American College of Obstetrician and Gynecologists (ACOG). During his career, he delivered over 19,000 babies! He was a member of the teaching faculty for St. Louis University School of Medicine, and Southern Illinois Medical School in Edwardsville Illinois. Dr. Graham and Dorothea have 6 living children. Dr. Graham died at his home in 1993 from lung cancer at the age of 75.

The first recipient of the award at the PLIDA 2006 conference was Laura A. Dean MD. Laura has a private OB practice. She is currently the youngest member of ACOG, and lives in Stillwater, Minnesota with her husband Matt and three young children.

The 2008 recipient is Dr. Robert Louis Becker. Dr. Becker has practiced medicine in St. Louis, Missouri for over 35 years. He was assistant professor of OB/GYN at Washington University School of Medicine, and currently serves on the boards of St. Johns Mercy Medical Center, and St. Luke's Hospital Women's Health Physicians. He is a member of the American college of Obstetrics and Gynecology and a Fellow in the American Fertility Society. Dr. Becker and his wife, Shirley, have five living children and one full term and one loss to miscarriage.

These two outstanding physicians were chosen by the six Grahams as representative of those who most emulated the dedication, ethics, passion, community service, and natural approach to obstetric care and who has demonstrated compassion for those suffering the loss of a baby. Their father, Dr. Graham, lived his life in a relationship-based model of patient care as Dr. Dean and Dr. Becker both have demonstrated. Any one wishing to nominate a Dr. please look on the PLIDA.org web site for the nomination process, to be chosen for the 2010 outstanding physician award. You may also email directly to:

[dorothacicch@yahoo.com](mailto:dorothacicch@yahoo.com)