



PLIDA Newsletter

Pregnancy Loss and Infant Death Alliance

Parent Support :: Advocacy :: Awareness :: Resources

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**Issue 5
Summer 2009**

Making Connections!

We hear you! Let's get connected—as individuals, as organizations, as people who feel passionately that bereaved families deserve high quality and compassionate care and support.

This issue of the PLIDA newsletter is full of new ways for all of us to stay connected to each other—to share our resources, ideas, concerns, and needs. We hope that you will find the method that helps you feel a part of PLIDA and connected your colleagues all over the world.

With *Spring* comes new beginnings and new growth. May this season find us all refreshed, renewed, and energized to do good work **together!**



Summer 2009



From the PLIDA Prez.....

What an incredible few months it has been. I imagine that since our time together at NPBC 2008, followed by the Board election, many of you are wondering just exactly what it is that PLIDA is doing. Well, let me give you a brief recap of what we've done, and a short peek ahead to where we are going.

The election of new Board members in January was an exciting time for PLIDA. While we gratefully wished our former board members Nicole Alston, Madonna Daley, Shirley Bulen, and Dorotha Cicchinelli good-bye, we also welcomed newly elected members, Emilie Lamberg Jones, Trish Wright, Kay McInnes, Mary Lee Lemley, and Lori Ives-Baine and welcomed Cathi Lammert back to the Board after a term away. You will hear from our new board members throughout this newsletter; I am confident that their enthusiasm, talents, and forward thinking are going to make PLIDA a thriving organization which will grow in both numbers and strength.

In early April, all former, new and current Board members gathered for a retreat outside Lexington, VA. We were blessed and honored by the generosity of Anne Grizzle who offered retreat space for us, and to Cheryl Persigal who facilitated our next round of organizational growth and strategic planning. We reviewed all the feedback from our membership meeting and created a working plan that captures the vision and energy of our membership and will create meaningful opportunities for members to connect not just at NPBC, but in many forums between conferences as well.



From the PLIDA Prez, continued:

And so, our work as a new Board has begun. We have several people working diligently on a refurbished Membership committee to create ways to link our members and build an infrastructure of information exchange and member-to-member support. We have others working on Conference and Strategic Partnerships to not only think about NPBC 2010, but also to work collaboratively and towards an expanded venue of offerings that bridges public health perspectives as well as hospital and community based bereavement support...you'll be hearing more from this committee soon, too.

Then, we have a group committed to PLIDA's Funding and Development, vital to the growth of our organization at this stage. Finally, the Governance committee was newly established and is working to create a smooth infrastructure through which future Board members and leaders can make good work happen in smooth and seamless ways.

I am humbled and honored to have been elected to PLIDA's Presidency during this time of growth and development. It is my sincere wish and goal to use my past work within the SIDS/maternal and child public health community to build strategic partnerships that can offer new ways to collaborate and expand our membership base. My current work as an academic researcher in Social Work affords the opportunity to blend a person-in-environment perspective to all we do: to launch new ways to bridge our work with individuals and families together with system level advocacy to create professional standards and policies that support PLIDA's mission. I am busy working on these goals, and open to any and all suggestions our members have. It is my great pleasure to work together with everyone during the coming two years.

Sarah Kye Price

Staying Connected

There are ever-changing ways to communicate in this age of new technology. We want to meet you **where and how you talk!**

On the phone...

Plan on a receiving a brief phone call from a board member in the coming months. We want to know how PLIDA can support your work, get feedback on what you want or need from PLIDA and how we can meet those needs. We also want to know about your amazing work so we can spread the word to our international members.

On the web...

PLIDA needs to meet you where you "etalk". We have recently set up new groups that you are encouraged to join, to share best practices, ask questions, and make suggestions so that the Board can keep in touch...

Online groups are easy ways to ask for help finding suggestions for memory makers, poems, and memorials with quick turn around time for your answers and potential for lots of feed back. Maybe there is a member in their area that wouldn't mind coming to a conference and helping out, find out who your neighbors are and use them to your benefit!

On **Facebook**, search for PLIDA Bereavement. On **Yahoo** groups, search for PLIDA Forum... Both groups are closed, meaning you will need to be accepted. We will be using our last known information for you to ensure you are a current PLIDA member. If your information is out of date (last update at the NPBC), please contact Lori Ives-Baine at lori.ives-baine@plida.org with updated info.

The facilitators of both groups will be working to ensure that the information on both is current and reflects the needs of our members.



Through this newsletter...

The PLIDA Newsletter is yet another way to stay informed and connected.

- Do you have a ***great idea*** to share?
- Are there legislative and/or advocacy announcements to make?
- Anyone know of good conferences for professionals or families?
- Have you been published lately or know of a great article to promote?

Share your resources by emailing them to newsletter@PLIDA.org



Sharing our Resources:

Select Perinatal Bereavement Supplies available free for your program...for information go to LLOST.org, campaigns and services, Treasured Memories Campaign.

If you are not familiar with Faith's Lodge, check out the link below. It's a beautiful facility in north central Wisconsin, built specifically to be a place of healing and reflection for parents who have a seriously ill child or who have experienced the death of a child. Costs to stay at the lodge are minimal, but certain criteria must be met.

If you know of anyone who might benefit from this getaway, please send them to the web site.

<http://www.faithslodge.org/>

Meet the Executive Committee

**Vice President
Cathi Lammert**



**Secretary
Lori Ives-Baine**



**Treasurer
Trish Wright**



**Past President
Beth Seyda**



**Membership Chair
Kay McInnes**



*I'm looking forward to the new changes to the Web site that are coming in the near future! We would like you to think about ways you can be involved and more active in PLIDA. Have you come up with creative ways of making memories for parents? Please e-mail and let us know we would love to share them with others. Remember with your **membership** you can Facebook or go to our Yahoo groups. Do you know someone else that might benefit from a **membership** with PLIDA, let them know! Be looking for a phone call from a board member to say Hi! And see if there is anything we can do to help you!*

Kay



Sharing our Resources

Monica Novak has been asked by Drs. Gloria and Heidi Horsley (of The Grief Blog and the radio show "Healing the Grieving Heart") to be the editor for the Open to Hope Pregnancy and Infant Loss blog page (www.opentohopepregnancyloss.com), a part of the Open to Hope network. Gloria and Heidi are the co-founders of Open to Hope, a national web-based grief foundation (www.opentohope.com). She is looking for contributors who would like to write and/or submit articles on the topics of miscarriage, stillbirth, infant death, planned termination, holidays and anniversaries, and general grief and loss issues pertaining to this topic. Monica, Cathi Lammert, Beth Seyda, and Irv Leon are just a few of the people already writing for this blog page. Not only is this a great resource for bereaved families and caregivers in this field, but Open to Hope provides another avenue for our contributing writers to get exposure for themselves, their books (if authors), and their organizations. Last year, more than one million people visited the Open to Hope main page, and the linked blog pages are gaining widespread exposure. For more information, please contact: Monica Novak Author, *The Good Grief Club* (www.thegoodgriefclub.com) Editor, *Open to Hope Pregnancy and Infant Loss page* (www.opentohopepregnancyloss.com)

Do you know about the PLIDA Resource List??

This annotated list of materials, organizations, and websites is not exhaustive, but meant to provide a good starting place for tapping into the vast array of available resources that can offer support, information, insights, and guidance.

PLIDA's Resources List includes: Books, Professional Periodicals and Bibliographies, Videos & DVDs, Parent Support Organizations, and Resource Centers

Go to: <http://www.plida.org/resources.html>

Legislative Updates and Advocacy:

First Candle Summary for PLIDA Member Newsletter
5-13-09

First Candle held a National Research & Advocacy Symposium in Washington DC on March 23-25, 2009. More than 150 parents, health professionals and leading researchers gathered to discuss current research efforts, preventive strategies and educational outreach programs. Pre-conference workshops were conducted by former PLIDA Board member Darryl Owens and PLIDA member Sherokee Ilse. One of the symposium sessions was an African American Clergy Breakfast that included a presentation by former PLIDA Board member Nicole Alston. Also participating in the symposium activities were PLIDA Board member Tammy Ruiz, PLIDA Past-President Beth Seyda, and PLIDA member Suzanne Pullen.

A day was also spent going to Capital Hill to advocate and garner support for pending Senate and House bills that would authorize appropriations for prevention, education and awareness of stillbirth and SIDS. More than 70 infant health advocates, including Beth, Suzanne, and Sherokee, met with more than 200 Congressional Representatives, US Senators, and health policy staff. All the staff thanked the advocates for taking the time to share their personal stories and tell them about the bills, and they greatly appreciated putting names and faces of parent constituents to the bills and not professional lobbyists. To learn more: <http://www.firstcandle.org/every-baby-deserves-a-first-birthday/2009-stillbirth-SIDS-SUID-research-and-advocacy-symposium/summary/summary.html>



The PLIDA Board has formed a new committee: **Board Governance and Development**. Its purpose is to ensure the consistent healthy functioning of the full Board.

Forming a governance committee is recommended by nonprofit board experts, for new and seasoned boards alike, as it is considered key to generating a Board of Directors that can effectively perform its work for the organization. PLIDA is a fairly new organization, and it's smart to get this up and running early in our development.

This committee's first priority is to write and maintain a *Board Process Manual*, which will give Board Members clear guidance and expectations for Board process, including roles, responsibilities, lines of communication, and decision-making authority. Through this Manual, the committee will be able to provide orientation and support to all Board members, so that serving on the Board is a productive and fulfilling experience. The end result will be that individuals on the Board remain energized and engaged in carrying out PLIDA's mission, and our organization and its members benefit.

For those PLIDA members who might be interested in this topic, there is a wealth of information and support out there for nonprofit Board governance. Here are the resources we've relied on:

Laughlin FL & Andringa RC. Good Governance for Nonprofits: Developing Principles and Policies for an Effective Board. Amacom, 2007

www.amanet.org

www.governancematters.org

www.boardsource.org

We also welcome any PLIDA members who have expertise in this area and would like to share their knowledge and insights with this committee. Or if you have other resources to recommend, we'd love to hear about them. Email the Gov Committee Chair, debbie.davis@plida.org



In the Media

The Gift by Bonnie Rochman
The Oprah Magazine - March 2009

“The health benefits of breast milk are well documented. Mothers with milk to spare can donate it to milk banks so infants -- especially preemies, who need it most -- can have this vital nourishment. But the milk of human kindness is often born of tragedy. Even when Lynn Page felt she'd lost everything, she still had something invaluable to give.”

http://www.oprah.com/article/omagazine/200903_omag_milk_bank

From the Conference Committee

The conference committee is hard at work in preparation for our 2010 conference. We are working collaboratively with the Association of SIDS and Infant Mortality Professionals (ASIP) to plan a joint 2010 conference that will be THE definitive conference on perinatal and infant death, from research and prevention to bereavement. We are narrowing down final conference dates and hotel sites in the Washington, DC region and are thrilled with the prospects this collaboration offers us for education, networking, advocacy and professional reflection. Details will be coming shortly. Please contact Sarah Kye Price, Conference Committee Chair for additional questions and information.

Book Review

Ahrens, T. with A. Bellephant & C. Bellephant. *Giant Hero: One couple's journey through loving and letting go of a son with Potter's Syndrome*. West Conshohocken, Penn: Infinity Publishing, 2008. (126 pages.) Funded by the University of Iowa Potter's Syndrome Research Group. The Bellephants have a website: www.gianthero.net

This richly woven book was authored by a journalist who got to know the Bellephant family during their pregnancy with baby Titus, who was diagnosed in utero with the fatal condition Potter's Syndrome (bilateral renal agenesis.) Filled with quotes and interviews from the parents Angie and Cecil, this book reflects their complicated journey of pregnancy and beyond: deciding to continue rather than terminate; the dread and joy that makes up the emotional rollercoaster of this kind of pregnancy and birth; decisions around NICU care when a baby is born early but in surprisingly good condition; the ultimate acceptance of the fatal diagnosis; the decision to let a beloved baby go and holding him until he dies; and the grief that follows death. Parents who are enduring or have endured a similar rollercoaster will find comfort in Angie and Cecil's story, which explores the common ground of bereavement and holds insights into the emotional complexities and agonizing decisions of parenting a baby who will die. They speak honestly about their positive and negative experiences with health care professionals, their efforts to be assertive and the benefits they reaped from compassionate, collaborative care. Practitioners can reap constructive guidance from this feedback.

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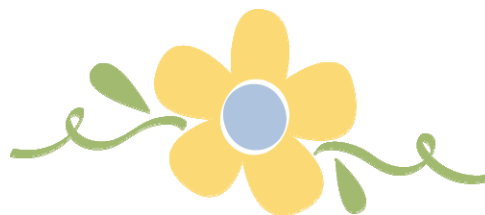
Book Review - continued

Angie and Cecil also talk about their faith, offering a window into their belief in miracles and coming to realize that “Faith is good, but faith is not the greatest thing, love is.” Cecil as a father, husband, and African-American man speaks eloquently about his own spiritual and emotional growth, and he offers hard won insights about grief and marriage for other dads. Angie speaks incisively about a mother’s special grief.

Even though the family set out to write a book for families whose babies are diagnosed with Potter’s Syndrome, their story can speak to any parent whose baby has a fatal condition. Also, it can resonate for fathers and mothers alike, and is appropriate for families from any spiritual tradition or cultural background. The final chapters include detailed medical information and resources on Potter’s Syndrome, heartfelt materials from Titus’s wake and funeral, and a list of tips from The Compassionate Friends about offering support to parents after their baby dies.

This book could have used judicious editing as it is repetitive, but it is easy to read and so full of information and emotional insights on such a wide range of topics, that it can be of great value to grieving parents.

**Reviewed for PLIDA and SHARE by Deborah L. Davis, PhD,
author of *Empty Cradle, Broken Heart* (Fulcrum): *Loving and Letting Go* (Centering): *A Gift of Time* (Johns Hopkins University Press, in 2010)**





In October of 2004, Pregnancy and Infant Loss Awareness month, *PLIDA* introduced a beautiful new pin. If you would like to order one of these graceful symbols of your remembrance and dedication, please contact us at (888)546-2828, press 3. The cost is \$6.00 per pin. **Pins can be ordered in bulk quantities at a discount and used as fundraisers for your organization.**

We hope you have enjoyed our Summer 2009 newsletter and found information in it to be beneficial. The *PLIDA* newsletter is free with your paid membership. If you have not renewed your membership, please visit our website and do so now so that you do not miss any future newsletters or other helpful information or articles. Visit us at www.PLIDA.org

