

Association of SIDS and Infant Mortality Programs

and

Pregnancy Loss and Infant Death Alliance

The International Conference on Perinatal and Infant Death

# Partners in

Prevention

Research

Advocacy

Support

November 4-7, 2010  
Washington, DC

**Intended Audience:**

**Professionals working in:**

- Maternal and Infant Health**
- Research**
- SUID/SIDS**
- Perinatal Health**
- Bereavement**
- Stillbirth**
- Public Health**
- FIMR**
- CDR**
- Home Visit Programs**



**Breakout Tracks**



**Prevention**



**Research**



**Advocacy**



**Support**

**Conference Continuing Education Credits**

Continuing Education Units and/or Contact Hours will be available upon request for conference participants. Attendees who engage in all conference plenary sessions and breakouts may be awarded an estimated 11.5 contact hours. Additional Contact Hours will be available for pre-conference attendees.

This activity has been submitted to the Virginia Nurses Association for approval to award contact hours. The Virginia Nurses Association is accredited as an approver of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation. Application is pending for 11.5 contact hours for nurses.

Virginia Commonwealth University, School of Social Work is a continuing education co-sponsor for the International Conference on Perinatal and Infant Death; Application is pending for 11.5 contact hours for social workers.

**Conference At A Glance**

**Thursday, November 4**

**Preconference**

- SUID/SIDS Program and Messaging
- NFIMR Training
- Pregnancy Following Perinatal Loss: Education and Support for Parents
- Perinatal Hospice
- Pregnancy Loss & The Arts Workshop

**Additional Trainings**

- National Share Training
- RTS Coordinator Training

6:00 p.m. Keynote Plenary

7:30 p.m. Reception & Networking Event

**Friday, November 5**

8:00 a.m. Gathering & Continental Breakfast

9:00-10:00 a.m. Welcome and Opening Session

10:00-11:15 a.m. Plenary Session

11:30-12:45 p.m. Luncheon-General Session

1:00-2:15 p.m. Breakout Session I

2:30-3:30 p.m. Afternoon Plenary

3:30-5:15 p.m. Research Panel

5:30-7:30 p.m. Poster Session & "Meet the Researchers" Reception

**Saturday, November 6**

7:45-8:45 a.m. Sunrise Cinema

8:00-9:00 a.m. Continental Breakfast

9:15-10:30 a.m. Morning Plenary

10:45-12:00 noon Breakout Session II

12:30-1:30 p.m. Membership Meeting Luncheon

1:45-3:00 p.m. Breakout Session III

3:15-4:30 p.m. Breakout Session IV

**Sunday, November 7**

9:00 a.m. Remembrance/Professional Acknowledgement Service

10:00 a.m. Breakfast

10:30-12:00 p.m. Closing Plenary

## Rates and Registration

Fees include attendance at all conference sessions, breakfast, and lunch, on the days for which you are registered. Your registration also includes all conference materials and access to the poster area. To receive the early registration rates, your registration must be completed online by September 30, 2010.

Cancellation policy: Full refunds, less a \$25 processing fee, are available only before September 30, 2010. To receive a refund, you must notify the conference management in writing by September 30, 2010, either by fax (517-485-0163) or email (asip@asip1.org). If you do not cancel by this date, payment in full is still due, even if you do not attend the conference.

For more information, email [asip@asip1.org](mailto:asip@asip1.org) or [info@plida.org](mailto:info@plida.org). All registration will be conducted online.

Category	Early Rate	Regular Rate
Pre-Conference	\$75 (Half day) \$150 (Full day)	\$75 (Half ) \$150 (Full)
Full Conference (Member)	\$395	\$445
Full Conference (Non-Member)	\$445	\$495
Day Registration	\$195	\$195

**\*Please be sure to renew your PLIDA or ASIP membership to receive the member rates!**

## REGISTER ONLINE

[CLICK HERE](#)

## Lodging

For your convenience, room blocks have been reserved at the Westin Alexandria hotel at a special rate of \$139 per night. Please book your room early; the group rate is only available until October 11, and rooms will fill quickly.

**Westin Alexandria**  
400 Courthouse Square  
Alexandria, Virginia 22314-5700

To receive the special rate, mention the conference when making your reservation. You may call Starwood Reservations at 866-837-4210 or contact the Westin Alexandria directly at 703-253-8600. Discounted rates are available for the nights of November 2 – November 10, 2010.

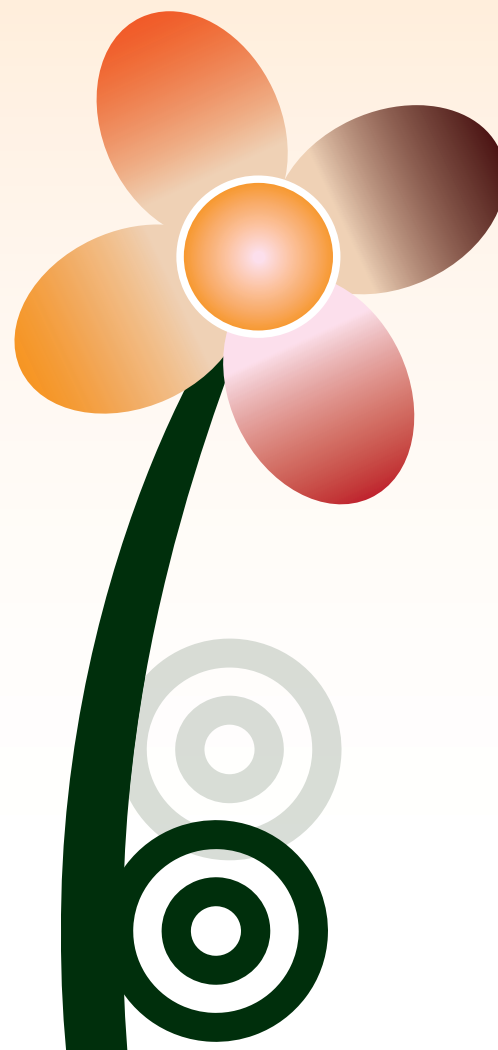
The Westin Alexandria blends sophistication and elegance with the historic surroundings of Alexandria, VA. Located in the exclusive Carlyle section of Old Town Alexandria, our hotel is a distinctive, upscale retreat. Three blocks from the King Street metro station and Alexandria Amtrak station, five miles from Ronald Reagan National Airport, and eight miles from downtown Washington, DC, our hotel is ideally situated for your visit to the Washington/Alexandria area.

## Area Attractions

To learn more about area attractions, please visit the following:

**Alexandria, VA** - <http://visitalexandriava.com>

**Washington, D.C.** - <http://washington.org/>



# Thank you to our 2010 Conference Planning Committee!

**Mary Adkins, RN, MSW, Conference Co-Chair**

Tomorrow's Child/Michigan SIDS

**Sandra J. Frank, JD, Conference Co-Chair**

Tomorrow's Child/Michigan SIDS

ASIP President

**Sarah Kye Price, PhD, MSW, Conference Co-Chair**

Virginia Commonwealth University

PLIDA President

**Cathi Lammert, RN, Conference Co-Chair**

Share Pregnancy and Infant Loss Support, Inc.

Executive Director

**Dorothea Cicchinelli, BASW, LCCE, CLC, MNM**

Colorado Pregnancy and Newborn Loss Services

**Anne Harvieux, MSW**

Infant Death Center of Wisconsin (ret.)

**Joann O'Leary, PhD, MPH, MS**

Parent-Infant Specialist, Writer

**Tammy Ruiz, RN**

Mary Washington Hospital

**Christy Schunn, LSCSW**

SIDS Network of Kansas, Inc.

## ABOUT US

### Association of SIDS and Infant Mortality Programs (ASIP) [www.asip1.org](http://www.asip1.org)

ASIP is a multidisciplinary professional membership organization whose members provide community education, training programs, and consultation for health departments, hospitals, emergency responders, medical examiners and law enforcement. The SIDS/ID professionals in ASIP (whose work addresses Sudden Infant Death Syndrome and Other Infant Death) represent a majority of the States, in many cases including the State SIDS/ID program director.

### Pregnancy Loss and Infant Death Alliance (PLIDA) [www.plida.org](http://www.plida.org)

The Pregnancy Loss and Infant Death Alliance has a unique purpose: to provide a formal network and a unified national presence to increase awareness and education on the emotional experiences and needs of bereaved families. PLIDA's goal is to become a central place for parent advocates, and interested professionals, media, and policy makers to find information on the emotional aspects of pregnancy loss and infant death. PLIDA also organizes the biennial International Perinatal Bereavement Conference.

**8:00 a.m. to 5:00 p.m.**

**Perinatal Hospice**

*Presenters: Lori Ives-Baine, RN MN, Tammy Ruiz, RN, Mary Peroutka, BSN, RN-OB*

An all-day session that will equip participants to develop or enhance the care that they can provide to families when a life-limiting condition has been identified, before, during or after birth. Our methods will be both instructive and collaborative to discern, teach and enhance best practice. Bring tools of your program (policies, handouts) to share. All disciplines welcome. Instructors are from the US and Canada.

**8:00 a.m. to 12:00 p.m.**

**Pregnancy Loss and The Arts**

*Laura Seftel, MPS, ATR-BC, LMHC*

A hands-on workshop by the author of "Grief Unseen: Healing Pregnancy Loss Through the Arts" will provide participants a greater depth of opportunity to discuss and demonstrate the inclusion of arts-based projects into their bereavement program.

**1:00 p.m. to 5:00 p.m.**

**Pregnancy Following Perinatal Loss: Education and Support for Parents**

*Joann O'Leary, PhD, MPH, MS; Jane Warland, PhD, RN, RM; Dorothea Cicchinelli, BASW, LCCE, CLC, MNM*

There is an abundance of literature on supporting families at the time of perinatal loss, yet parents' needs in the pregnancy that follows is less understood. This half-day pre-conference workshop summarizes the research on pregnancy following perinatal loss and presents a prenatal attachment model of intervention, interweaving nurse/midwife management with parents' psycho-social needs as they prepare for the birth of a new baby. Content will address childbirth and postpartum education and facilitation of a support group.

**1:00 p.m. to 5:00 p.m.**

**Hot Topics in Infant Safe Sleep**

*Rachel Moon, MD, Children's National Medical Center*

*Chair, AAP Task Force on SIDS and Infant Sleep Position*

Not sure about the Safe Sleep message? Confused by conflicting recommendations? Frustrated because parents don't listen? Conflicted by your personal beliefs? What about cultural concerns? We're putting the hot topics out there and giving you a chance to talk about them. One of the nation's leading experts, Dr. Rachel Moon, will conduct an extensive, interactive workshop and facilitate the conversation. In response to the challenges from the field, Dr. Moon will discuss the research, cultural issues, and evidence. A report will be developed from the workshop proceedings. If you work with Infant Safe Sleep, you will not want to miss this session!

Bring your experience, questions, and ideas about:

Bedsharing  
Breastfeeding  
Reflux  
Swaddling  
Bumpers

# ADDITIONAL TRAINING OPPORTUNITIES

## **NFIMR Training**

### **Cultural and Linguistic Competence Organizational Self-Assessment for Fetal Infant**

#### **Mortality Review Programs: Why and How**

*Suzanne M. Bronheim, PhD*

The Cultural and Linguistic Competence Organizational Assessment Instrument for Fetal and Infant Mortality Review Programs (CLCOA-FIMR) was developed by the National Center for Cultural Competence (NCCC) in collaboration with the National Fetal and Infant Mortality Review Program with guidance from a national workgroup of state and local FIMR representatives. It is intended to support FIMRs to: (1) plan for and incorporate culturally and linguistically competent policies, structures, and practices in all aspects of their work; (2) enhance the quality of case reviews and action plans within diverse and underserved communities; and (3) promote cultural and linguistic competence as an essential approach in the elimination of disparities and the promotion of health and mental health equity. This half day workshop will provide participants with information about the tool, its content and how to use. In addition, the workshop will cover the process for a successful self-assessment, how to move from assessment findings to action and resources to learn more about cultural and linguistic competence. Sponsored by NFIMR and offered free to FIMR members. To register for this preconference session, please click [here](#). To register for the ASIP/PLIDA Conference plenary and breakout sessions, please see page two of this brochure.

---

The International Conference on Perinatal and Infant Death is pleased to support the efforts of Bereavement Services and Share Pregnancy and Infant Loss Support by inviting both to conduct additional trainings on Thursday, November 4th. These additional training opportunities are described below. Registration and fees are separate from the ICPID. Please contact the sponsoring organizations' websites directly for more information.

### **Resolve Through Sharing (RTS) Coordinator Training**

*Rana Limbo, PhD, RN, PMHCNS-BC and Kathie Kobler, MS, APN PCNS-BC*

**Pre-requisite:** *Completion of Resolve Through Sharing Bereavement Training in early pregnancy loss, stillbirth, and newborn death.*

Since 1985, RTS has offered Coordinator Training to over 4,000 individuals. This one-day course, which is updated and enhanced at least every other year, provides quality education and leadership training. It is designed to teach the skills necessary to implement and maintain the RTS perinatal bereavement program. RTS Coordinator Training focuses on the role of the interdisciplinary team, addresses leadership, program implementation, change and conflict, and the importance of administrative support. It incorporates adult learning principles and focuses on effective teaching strategies. You may register online at [www.bereavementservices.org](http://www.bereavementservices.org), or call us at 800-362-9567, Ext. 54747 or Ext. 53568. Visit our Web site for information on continuing education, cancellation, or to learn more about the course.

---

## **National Share Training**

### **Keeping Your Support Group on Track**

*Cathi Lammert, RN and Megan Nichols*

This session explores creative ways to better manage a support group and provide means to confront challenges that arise in this setting. In addition, attendees will be given concrete ideas to expanding the support group's mission. Participants will have opportunity to interact with other support group coordinators and share their experiences.

### **Establishing and Maintaining a Share Peer Companion Program**

*Cathi Lammert, RN*

This afternoon session illustrates directives for organizing and managing a Share Peer Companion Program that provides support to bereaved families at the time of their loss and throughout the grief process.

*Share Preconferences are open to parent advocates and professionals who have attended Sharing and Caring Training or have managed for a minimum of three years a support group/bereavement program for bereaved families experiencing the death of a baby during the pregnancy, at birth or in the first few months of life. Contact National Share Office at 800-821-6819 or view application at <http://www.nationalsshare.org/ICPID-Share-PreCon.html>*

# The International Conference on Perinatal and Infant Death

*Partners in Prevention, Research, Advocacy and Support*

Conference Sessions

**Thursday - November 4, 2010**

7:00 a.m.

Registration desk open

6:00 p.m.

Welcome  
Opening Keynote Plenary

**New Research: Bereavement Care After Pregnancy and Infant Loss**

*Katherine Gold, MD, MSW*

7:30 p.m.

Welcome Reception

**Friday - November 5, 2010**

7:00 a.m.

Registration desk open

8:00 a.m. to 9:00 a.m.

Continental Breakfast

9:00 a.m. to 10:00 a.m.

**Welcome and Opening Session**

*Peter van Dyck, MD, MPH (invited)*

Associate Administrator for Maternal and Child Health

Health Resources and Services Administration

U.S. Department of Health and Human Services

*Michael Fraser, PhD, CAE*

Chief Executive Officer

Association of Maternal and Child Health Programs

10:00 a.m. to 11:15 a.m.

**Plenary Session**

**The Life Course Perspective: Redefining Maternal and Child Health**

*Michael Lu, MD, MPH*

Doctors and researchers are increasingly learning that by the time a woman gets pregnant, she may have already missed a critical window of opportunity to give her baby the best start in life. Dr. Lu will describe his life course perspective theory which takes a broader look at the complexities, health factors and stressors affecting maternal and infant health. The session will describe the racial and ethnic disparities in birth outcomes and the factors impacting disparities. Participants will be able identify strategies that to reduce racial and ethnic disparity in birth outcomes.

11:30 a.m. to 12:45 p.m.

**Lunch Plenary Session**

**How Real Men Grieve**

*John D. Canine, EdD, PhD*

1:00 p.m. to 2:15 p.m.

## Breakout I

### 1) Focus on Fatherhood: The Male Contribution to a Healthy Pregnancy Outcome P R

*Michael Lu, MD, MPH*

The session will explore the male role and how the father contributes to a healthy pregnancy outcome. The presentation will include preconception care for men, barriers to male involvement, and the Recommendations from the Commission on Paternal Involvement in Pregnancy Outcomes.

### 2) Panel: Ethical and Social Implications of Genetic Testing in the Case of Sudden Unexplained Deaths R

*Siobhan M. Dolan, MD, MPH, Robert w. Marion, MD, Thomas V. McDonald, MD, David T. Wasserman, JD, MA*

A panel session will outline the landscape of cardiogenetics in sudden death and explore family and ethical issues that arise in providing clinical care for these families. A question and answer session with audience members will follow.

### 3) Advocating for Maternal and Child Health: Pitfalls, Perils, And Partnerships A P

*Brent Ewig, MHS and Joshua Brown*

The workshop will describe The Association of Maternal and Child Health Programs (AMCHP) ongoing work to advocate for maternal and child health issues through health reform. Included are advocacy efforts to increase national and local support and funding for maternal and child health programs, and give examples of how advocacy can be used to promote home visiting and a variety of maternal and child health issues.

### 4) Caring Connections: Nurse Home Visit Intervention in Pregnancy after Perinatal Loss S R

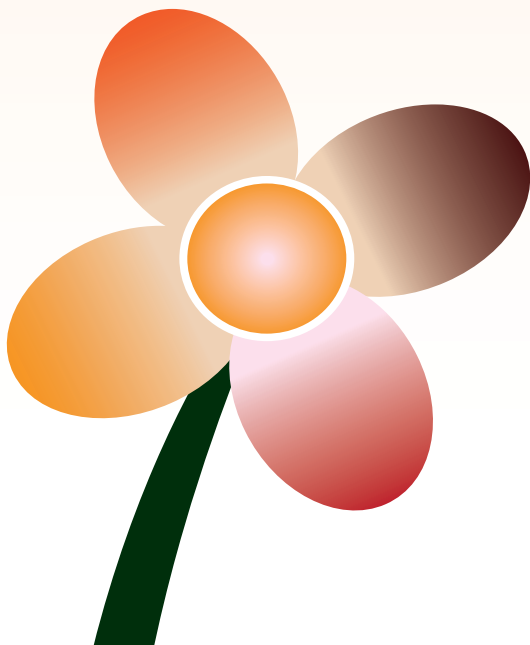
*Denise Côté-Arsenault, PhD, RNC, FNAP*

This session focusing on subsequent pregnancy after loss features a detailed background, literature review, theoretical framework, research methods, findings and conclusions of a pilot intervention study for women pregnant after perinatal loss. Personal experiences with the intervention and discussion opportunities are offered. Intermediate Level.

### 5) Panel: An Essential Place to Start S

*Beth Seyda and Marcia Jenkins, RN*

The session highlights several experts on perinatal bereavement integrating insights from bereaved families with perinatal loss research/literature to illustrate the challenges that families face during/after a loss, ways healthcare providers can support families, and opportunities to improve healthcare teams. A panel of volunteer companions will offer insights in how to create and sustain a volunteer grief companion program. Basic Level.



## 6) Early Pregnancy Loss: Supporting Today's Women and Families Who Experience Miscarriage

*Sandy Maclean, B.S. and Elizabeth Levang, PhD*

While early pregnancy losses are the most frequent type of perinatal loss, our focus on them has often been lacking. Women and their partners often suffer in silence when pregnancy ends in miscarriage. The presentation will address the realities and challenges experienced by today's women and discuss innovative strategies for improving care before, during and after an early pregnancy loss.

## 7) Walking in My Shoes

*Lori Ives-Baine, RN, MN (CPB), Gail Lindsay, RN, PhD, Nadine Cross, RN, MN, PhD and Jonathan Hellmann, MD*

In perinatal grief we seldom focus on those who care for our patients. We studied the experiences of nurses in a Level 3/4 NICU who cared for families babies and their babies through their death. The presentation will include research and look at its implications in the clinical field. The research will be applicable in many clinical situations to support the professionals in these roles.

**2:30 p.m. to 3:30 p.m.**

### **Plenary Session**

#### **Advances in SIDS and Stillbirth Research**

*Marion Willinger, PhD*

#### **New Research: Unraveling the Mystery of SIDS and Stillbirth**

*David Patterson, MD*

**3:30 p.m. to 5:15 p.m.**

### **Plenary Session Research Panel**

*Rachel Moon, MD; Katherine Gold, MD, MSW; Sarah Kye Price, PhD, MSW; Marian Willinger, PhD; and David Patterson, MD*

A panel of leading experts will provide a synopsis of research on sudden unexpected infant death, perinatal death and bereavement. Panelists will review various approaches to understanding the science and looking at evidence from various perspectives across the continuum. A question and answer session will follow.

**5:30 p.m. to 7:30 p.m.**

### **Reception: Meet the Researchers and Poster Session**

Researchers will join us for our Innovative Program and Research Poster Session. This will be your opportunity to hear and talk with national experts. View and discuss the featured posters including:

- Reasons that African-American Parents Use Soft Bedding and Soft Sleep Surfaces for their Infant
- Factors Influencing Swaddling Practices
- PALS (Parenting After Loss Support) Program
- FIMR Programs: Promoting Cultural and Linguistically Health Education Messages in Multi - Cultural Communities
- Pacifiers and SIDS Risk: Would Parents Change Their Mind If They Knew?
- Breast Milk Donation Program for Bereaved Mothers
- Prevalence of Psychiatric Disorders and Substance Use in Stillbirth
- Who Sees or Holds Their Baby? Parental Experiences after Stillbirth
- By My Side Just One Last Time
- Ethical Issues and Decision-Making
- When the Fight for Life is Beyond Reach
- Infant Sleeping Position in Virginia
- Implementation of a Standardized Safe Sleep Message
- Periods of PURPLE Crying: Innovations in Preventing Shaken Baby Syndrome
- Nurses as Models for Promotion of Safe Sleep Environment

# Saturday - November 6, 2010

7:45 - 8:45 a.m.

Sunrise Cinema

Start the conference day with a viewing of films for professional use with bereaved families and caregivers. Bring your coffee and breakfast to view and discuss the latest releases of video, including those from Beth Seyda, Sherokee Isle, and Christine Jonas-Simpson.

8:00 a.m. to 9:00 a.m.

Continental Breakfast

9:00 a.m. to 9:15 a.m.

Welcome and Announcements

9:15 a.m. to 10:30 a.m.

Plenary Session

**Being in Relationship**

*Rana Limbo, PhD, RN, PMHCNS-BC and Kathie Kobler, MS, APN, PCNS-BC*

Appropriately using “self” in work with bereaved parents is a fundamental component of relationship-based care. Engaging with bereaved families as a health care professional or parent advocate requires preparation and reflective work before the relationship begins. The effective use of self can be optimized in a relationship through continued reflective practice. The speakers use narratives, visual media, and case studies to engage the audience in exploring the “how-to” of relationship-based care, balancing perspectives of “self” and those of the family. They discuss self awareness, self-care, compassionate silence, and using relationship to co-create ritual.

10:45 a.m. to 12:00 p.m.

## Breakout II

### 1) Follow-up to Being in Relationship: Small Group Work

*Rana Limbo, PhD, RN and Kathie Kobler, MS, APN*

This interactive workshop will provide an opportunity for participants to further explore topics from the general session, Being in Relationship. Workshop participants will work in small groups and dyads, with large group discussion facilitated by the speakers. The interactive format will include opportunities to discuss individualized strategies to develop a reflective practice, share personal experiences within professional relationships, increase sensitivity to a family’s perspectives, and enhance self-care and self awareness. The workshop’s emphasis is on personal discovery and insight.

### 2) SIDS Risk Reduction in Indigenous Populations from a National and State Perspective

#### Healthy Native Babies Project

*Shavon Artis, MPH, and Jennifer Irving*

NICHD’s Healthy Native Babies Project provides Sudden Infant Death Syndrome risk-reduction messages to American Indians and Alaska natives via culturally and regionally appropriate training and outreach materials to tackle the high SIDS rate for this population.

### Bed Sharing and Infant Safe Sleep in Alaska: Building a Culturally Relevant Prevention Model

*Debra Golden, RN, BC, MS*

Bed sharing is a controversial aspect of efforts to reduce infant sleep-related death. Alaska conducted a study of infant sleep-related deaths and, based on findings, started an Infant Safe Sleep (ISS) Initiative. The presentation will present the findings, interventions, and next steps which include focus groups, development of social marketing products, and strategies to integrate and sustain the message. Basic-Intermediate Level.

## Breakout II ~ continued

### 3) **Care Across America: The March of Dimes NICU Family Support Bereavement Model** *Victoria Leland, RN, BSN*

The session will present a compelling summation of replicable modes of support for bereaved NICU families that have emerged across the country within the March of Dimes NICU Family Support Program. Because the March of Dimes partners with a wide variety of hospitals who serve very diverse patient demographic groups, modes of support that will be discussed are impactful, well vetted, and culturally sensitive.

### 4) **Updates on Federal SIDS and SUID Initiatives**

#### **Consumer Product Safety Commission**

*Michelle Faust Gillice, JD*

CPSC will provide an update on its SIDS and Infant Safe Sleep Campaign which includes:

- Safe Sleep literature
- Safe Sleep Messaging using Social Media and CPSC blogs
- Minority Outreach to African Americans; Native Americans, Asian Americans, and Hispanic Community

#### **Center for Disease Control: Sudden Unexpected Infant Death Case Registry**

*Carrie Shapiro-Mendoza, PhD*

The session will provide a description and update on the Center for Disease Control Sudden Unexpected Infant Death Case Registry pilot program which aims to generate public health surveillance information at the state and local levels that can comprehensively describe the circumstances and events surrounding SUID cases. The presentation will include a review of the five states awarded funds to participate in the CDC SUID Case Registry Pilot Program.

#### **National SUID Centers**

The federal Maternal and Child Health Bureau supports four national centers that address sudden unexpected infant death: SUID Resource Center, Program Support Center, Project IMPACT, and the SUID Project at the National Center for Cultural Competence. The session will provide a summary of the resources and services offered by each center

### 5) **Commitment and Promise: The Power of Stillbirth Assessment** *Jane Heustis RN, BSN and Marcia Jenkins, RN, ASN*

Stillbirth is remarkably common yet in most cases the cause of death of baby remains a mystery. Parents often struggle in making decisions about postmortem testing and frequently decline. The 'why' questions about their loss can be an impediment in their journey of grief. The workshop will explore the process of stillbirth assessment and offer ways to provide a systematic stillbirth assessment program in their own community.

### 6) **What About the Children?**

*Joann O'Leary, PhD, MPH, MS; and Jane Warland, PhD, RN, RM* 

Infant loss affects approximately 30% of all families and is said to be the most devastating experience a parent will ever go through. It can have a significant impact on siblings at the time of loss, in the pregnancy that follows, for children born after the loss and long term parenting behaviors. This intermediate-advanced session will present findings from qualitative studies of parents raising children after a perinatal loss, siblings alive at the time of the loss, and the subsequent children. Interventions for health family development will be discussed.

12:30 p.m. to 1:30 p.m.

Lunch

PLIDA and ASIP Membership Meetings

1:45 p.m. to 3:00 p.m.

## Breakout III

### 1) Safe Sleep in the Hospital Setting

#### **Institutionalizing Infant Safe Sleep in the Hospital Setting** **R** **P**

*Mary Adkins, RN, MSW*

*Sandra Frank, JD, CAE*

The session will present findings from the pilot phase of the Michigan Infant Safe Sleep Hospital Model (2004-2007). An independent evaluator developed tools and procedures to assess and modify hospital policies, collect data on nurse and patient knowledge of safe sleep, conduct pre and post tests, and analyze data. The presentation will include evaluation findings involving 2739 crib audits, 2678 patients, and 635 nurses. Participants will learn about successful strategies to institutionalize and evaluate infant safe sleep in the hospital setting, and to change knowledge and behavior of nurses. Advanced Level.

#### **Hospital Outreach and Partnership for Education about Infant Safe Sleep (HOPES)** **P**

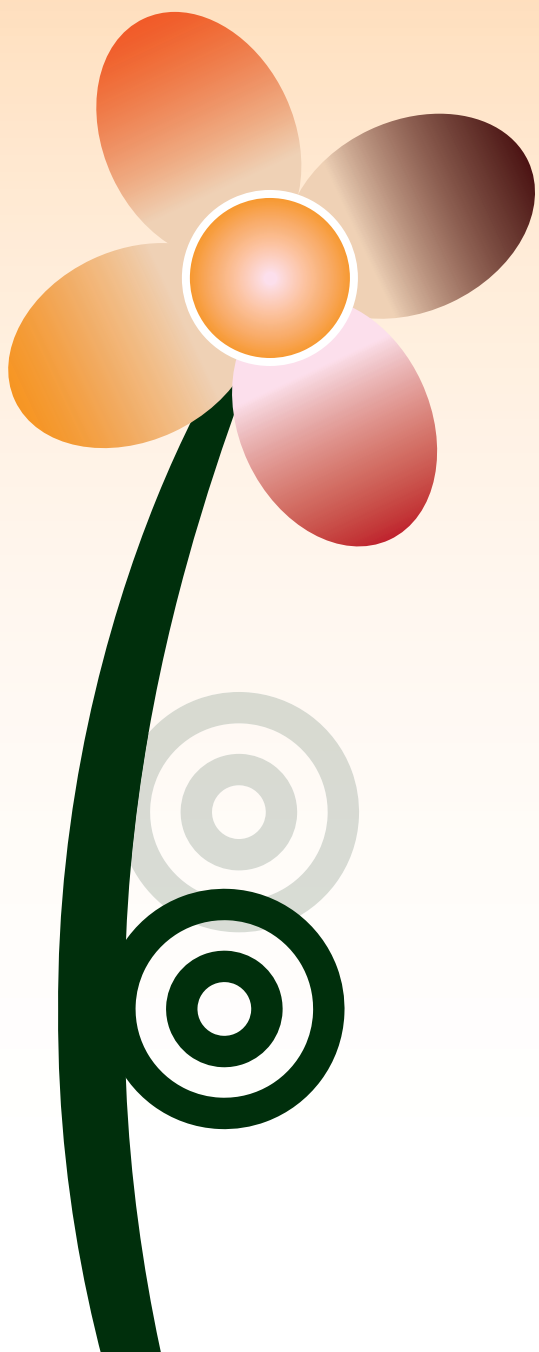
*Marta Pirzadeh*

The Hospital Outreach and Partnerships for Education about Infant Safe Sleep (HOPES) program is a hospital-based education and prevention program with the goal of institutionalizing infant safe sleep practices and policy in hospitals across North Carolina. This presentation will discuss the success and challenges with HOPES and provide participants with the background to begin a similar process. Basic level.

#### **2) Challenges We Face, Answers We Share: Interactive Program Workshop Session** **S**

*Sherokee Ilse, BA, Pam Magi, RN, Suzanne Helzer and Suzanne Pullen*

An interactive workshop designed to discover the needs and challenges facing participants in their hospital-based bereavement programs. While the facilitators will have 4-6 topics in mind, the participants will be polled to discover additional topics the group has interest in discussing. These 'challenges' will become 'Table Topics' for a series of four 15 minute mini-sessions. Participants will rotate to new tables with different topics and add to a list of "obstacles," "concerns," and "possible solutions" at each table. Participants will reconvene and spend the remaining time reviewing the obstacles, roadblocks, and creative solutions that emerged. Intermediate-Advanced Level.



### 3) Research on Maternal Experiences of Bereavement and Depression (2 papers)

#### **Paper #1: Pushing On: A grounded theory study of maternal perinatal bereavement**

*Patricia Moyle Wright, PhD, RN*

The aim of this classic grounded theory study was to develop a substantive theory of maternal perinatal bereavement. Data were collected through interviews with women who had experienced losses. Data analysis resulted in the discovery of a 5-stage theory that involved experiencing the pregnancy, losing the baby, bearing the burden, working through the pain, and transcending the suffering.

#### **Paper #2: The Role of Perinatal Loss History in Low Income Women's Help-Seeking for Depression**

*Sarah Kye Price, PhD, MSW*

Low income and ethnic minority women are disproportionately affected by both fetal and infant mortality, and mental health symptoms during and around the time of pregnancy. This research presentation is designed to bring together research regarding the experiences of perinatal depression as well as perinatal and infant death in communities of highest risk. The author will present original research as well as situate that research in a larger context in order to advance a research agenda that allows for greater understanding of women's mental health during and around the time of pregnancy.

### 4) This is Not What We Were Expecting: A Focus on Prenatal Decisions

*Nancy A. Goldin, LCSW and Susan Rizzato, MSW, LCSW*

This basic-intermediate level session focuses on working with parents who are faced with the difficult decision to terminate a pregnancy because of genetic or chromosomal abnormalities or severe medical problems with their baby. The discussion will include the emotional, cultural, and moral complexities faced by this population. Strategies for effective intervention will be explored in ways that maximize sensitivity and self-determination.

### 5) Panel: International and Cross-Cultural Perspectives on Bereavement Support

*Vicki Culling, PhD:* Through the exploration of best practice around perinatal and infant death from another country, health professionals have the opportunity to reflect on their practice and consider approaches of others. The presentation will offer a model of care as well as illustrate best practice through illustrations from a New Zealand family.

*Ariella Lang, RN, PhD; Fabie Duhamel RN, PhD; Wendy Sword RN, PhD; Kathleen R. Gilbert PhD; Megan Aston RN, PhD; Andrea R. Fleischer RN, BSc, BN, PhD Student:*

This presentation will discuss the development of a best practice primary bereavement guideline implemented in Quebec, and how the recommendations can be specifically applied to perinatal bereavement. The project intends to emphasize health promotion following a loss and during the bereavement process rather than focus on the negative outcomes associated with bereavement.

*Francine de Montigny, PhD and Chantal Verdon, PhD:*

This segment of the presentation will describe the services offered to bereaved parents in Quebec including the results of a phone survey of one hundred fifty four health institutions in Quebec regarding what services were offered to bereaved parents.



3:15 p.m. to 4:30 p.m

## Breakout IV

### 1) Evaluating Crib Distribution and Safe Sleep Prevention: Evaluation Studies **R**

*Nadine Goldberg, PhD, MS*

This session will explore the challenges and lessons learned in implementing a large crib distribution and safe sleep education program in three sites with diverse populations, coalitions, and organizations: Indiana, Washington state and Washington DC. Topics covered will include identifying community partners, obtaining IRB approval, and developing evaluation tools. Data collection methodology and early survey results will be presented in detail.

### 2) She Sat With Us While We Cried: Interactive Performance of Provider/Bereaved Parent Interactions **S R**

*Suzanne Pullen*

This innovative and interactive presentation features an ethnographic performance of stillbirth patients' experiences and their interactions with care providers. Using audience participation and mixed method research excerpts, the session creates opportunities for embodied understanding, increased patient-centered communication and research-based recommendations for bereavement care.

### 3) Research on Parental Experiences of Fetal and Infant Death (2 papers) **R**

#### Paper #1: The Challenges of Ambiguity and Disenfranchisement Following Fetal/infant Death

*Ariella Lang RN, PhD, Andrea R. Fleischer RN, BSc, BN, PhD Student, Fabie Duhamel RN, PhD, Wendy Sword RN, PhD, Kathleen R. Gilbert PhD, and Serena Corsini-Munt MA*

This presentation will outline the experiences of bereaved families following a perinatal loss, and how these experiences are wrought with ambiguity and a sense of disenfranchisement. This study intends to highlight the complexities of perinatal loss, and inform our understanding of the significance of the interactions between the bereaved couple and their healthcare professionals, their families and loved ones, and within the parental dyad.

#### Paper #2: Affirming Motherhood: Lessons from Mothers' Narratives of Perinatal Hospice

*Anthony Lathrop, RN, CNM, PhD*

Perinatal hospice (PH) is a model of care for families who choose to continue pregnancies after learning of a life-limiting fetal condition. This presentation will include findings from a groundbreaking study that explored PH mothers' experiences during pregnancy, in childbirth and the newborn period, and after the deaths of their infants. The speaker will discuss models and strategies for supportive care in the hospital, ambulatory, and community settings, as well as needs for future research and program development.

### 4) Meaning Making: Parents' Stories of Other Rituals **S**

*Todd Hochberg*

Four families will share their unique stories of loss and non-traditional rituals. Ranging from a participatory funeral where family members take part in casket building or burial to lovingly created memorial tattoos. Through photographs, audio and video, participants will gain an understanding of the meaning-making value of ritual for bereaved families and the emotional space necessary for this creativity.

## Breakout IV ~ continued

### 5) **Online Peer Support Groups for Perinatal Loss and Infant Death: Research Meets Real World**

*Elizabeth A. Pector, MD, FAAFP and Cathi Lammert, RN*

In a lecture with audience participation, attendees explore rewards and challenges of hosting online peer groups for pregnancy and infant loss. First, we look at a decade's evolution of online group structure and group process. A research review of benefits, limitations and risks of online groups leads into highlights of the moderator's role, effective guidelines, and management of crises and difficult interactions.

### 6) **Cultural Diversity in Experiences of Perinatal Grief and Loss**

*Judi Vitucci, ARNP, PhD*

This presentation gives an overview of various cultural traditions participants might encounter when families are grieving the loss of an infant. Through case studies, group activities and lecture, cultural diversity and spiritual beliefs reflected in expressions of perinatal grief and loss will be explored including shared personal experiences of cross-cultural norms.

## Sunday - November 7, 2010

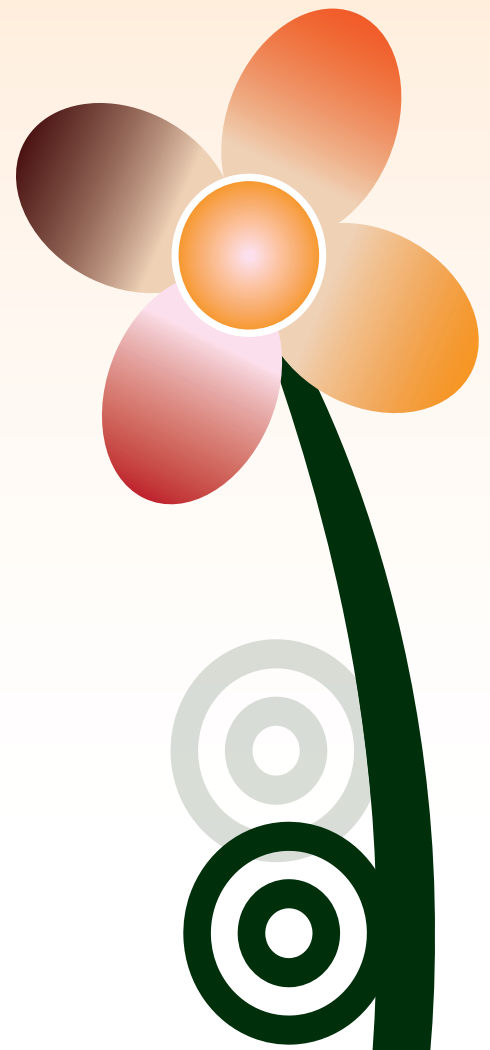
### 9:00 a.m. **Remembrance/Professional Acknowledgement Service**

We are not only professionals, but also caring human beings who support, research, advocate, and engage in health promotion activities that have a meaningfully impact on the lives of others. We encourage you to take some reflective moments to recharge yourself, acknowledge the importance of your work, and honor the lives that inspire and are touched by what we do. This remembrance and acknowledgement service will honor the personal and the professional aspects of our daily lives and work.

### 10:00 a.m. **Breakfast**

### 10:30 a.m. to 12:00 p.m. **Closing Plenary Session** **John O'Leary**

Journey with John O'Leary as he powerfully reveals how our greatest challenges can be transformed into outstanding growth. Through emotional story-telling and great humor, John will empower you to move past your comfort zone, dream big and take action. John intimately shares his personal story of surviving a childhood fire which burned 100% of his body. As proof of the power of the human spirit, John will re-ignite your life!



**Questions? Contact ASIP at 800.930.7437 or PLIDA at 888.546.2828 Ext. 3.**

**Association of SIDS and Infant Mortality Programs**  
112 East Allegan St. Suite 500  
Lansing, MI 48933  
[www.asip1.org](http://www.asip1.org)  
800.930.7437