# Perinatal Loss: Resources for Providers

### Pregnancy Loss and Infant Death Alliance <a href="http://www.plida.org/resources.php">www.plida.org/resources.php</a>

PLIDA maintains a comprehensive list of resources related to perinatal death and perinatal palliative care. The list contains resources for both families and providers, and it is updated annually.

## Association of SIDS and Infant Mortality Programs (ASIP) www.asip1.org

The Association of SIDS and Infant Mortality Programs (ASIP) provides national leadership to establish and promote policy and practices for professionals who respond to infant and child death and is committed to bereavement support, risk reduction and prevention services. ASIP directs the National SIDS and Infant Death Project IMPACT to help disseminate bereavement and risk reduction information.

### American Academy of Hospice and Palliative Care Medicine www.aahpm.org

Website of the professional organization of physicians and other medical professionals dedicated to expanding access for patients and families to high quality palliative care, and advancing the discipline of Hospice and Palliative Medicine, through professional education and training, development of a specialist workforce, support for clinical practice standards, research and public policy.

#### Bereavement Services (RTS) www.bereavementprogams.com

Bereavement-related training and support materials for health professionals in all disciplines. **Centering Corporation** <u>www.centering.org</u>

Publisher and distributor of grief resources, including materials focused specifically on pregnancy loss and infant death. Some available in Spanish.

**Children's Project on Palliative/Hospice Services (ChiPPS)** <u>www.nhpco.org/pediatrics</u> Group of medical professionals initiated by the National Hospice and Palliative Care Organization. Quarterly newsletter available online, Issues 6 and 7 (2007) focus on perinatal palliative care: <u>http://www.nhcpo.org/i4a/pages/index.cfm?pageID=4657</u>

Grief Watch www.griefwatch.com/pl/pro/default.htm

Publishes and distributes materials for bereaved families.

### March of Dimes www.marchofdimes.com

The March of Dimes is dedicated to improving infant health by preventing birth defects, premature birth, and infant mortality through research, community services, education, and advocacy.

A comprehensive bibliography about perinatal bereavement, parent support, relationshipbased care, and subsequent pregnancy/parenting is available at <u>www.plida.org/resources.php</u>. Below is a selection of references from peer-reviewed journals focusing on perinatal bereavement and palliative care services and programs:

- Calhoun BC, Napolitano P, Terry M, Bussey C, Hoeldtke NJ. Perinatal hospice: comprehensive care for the family of the fetus with a lethal condition. *J Reproduc Med* May 2003;48(5):343-8.
- Calhoun BC, Hoeldtke NJ. The perinatal hospice: ploughing the field of natal sorrow. *Frontiers in Fetal Health* 2000;2(5). (Not peer-reviewed)

- Callister LC. Perinatal loss: a family perspective. *J Perinat Neonat Nurs* Jul/Sep 2006;20(3):227-34.
- Capitulo KL. Evidence for healing interventions with perinatal bereavement. *MCN Am J Matern Child Nurs* 2005;30(6):389-96.
- Catlin A, Carter B. Creation of a neonatal end-of-life protocol. *J Perinatol* 2002;22:184-95.
- Davis DL. Providing emotionally supportive care to parents as they face decisions after prenatal diagnosis of a baby's life-limiting condition. *CHiPPS Pediatric Palliative Care Newsletter*. 2007;7:22-5. (Not peer-reviewed)
- Davis DL, Stewart M, Harmon RJ. Perinatal loss: providing emotional support for bereaved parents.*Birth* 1988;15(4):242-6.
- Gold KJ, Dalton VK, Schwenk TL. Hospital care for parents after perinatal death. *Obstet Gynecol* May 2007;109(5):1156-66.
- Gold KJ. Navigating care after a baby dies: a systematic review of parent experiences with health providers. *J Perinat* 2007;27:230-7.
- Hoeldtke NJ, Calhoun BC. Perinatal hospice. Am J Obstet Gynecol Sep 2001;185(3):525-9.
- Howard ED. Family-centered care in the context of a fetal abnormality. *J Perinat Neonat Nurs*2006;20(3):237-42.
- Hughes P, Riches S. Psychological aspects of perinatal loss. *Curr Opin Obstet Gynecol* Apr 2003;15(2): 107-11.
- Hughes P, Turton P, Hopper E, Evans CD. Assessment of guidelines for good practice in psychosocial care of mothers after stillbirth: a cohort study. *Lancet* Jul 2002;360(9327):114-8.
- Kavanaugh K, Hershberger P. Perinatal loss in low-income African-American parents. *J Obstet Gynecol Neonatal Nurs* Sep/Oct 2005;34(5):595-605.
- Kavanaugh K, Moro T. Supporting parents after a stillbirth or newborn death: there is much that nurses can do. *Am J Nurs* Sep 2006;106(9):74-9.
- Kavanaugh K, Trier D, Korzec M. Social support following perinatal loss. *J Fam Nurs* Feb 2004;10(1):70-92.
- Kobler K, Limbo R, Kavanaugh K. Meaningful moments: the use of ritual in perinatal and pediatric death. *MCN Am J Matern Child Nurs* Sep/Oct 2007;32(5):288-95.
- Leon IG. Perinatal loss: a critique of current hospital practices. *Clin Pediatr* 1992;31(6):366-74.
- Leuthner SR. Fetal palliative care. *Clin Perinatol* 2004;31:649-65.
- Leuthner SR. Palliative care of the infant with lethal anomalies. *Pediatr Clin N Am* 2004;51:747-59.
- Leuthner SR, Pierucci R. Experience with neonatal palliative care consultation at the Medical College of Wisconsin-Children's Hospital of Wisconsin. *J Palliat Med* Nov 2001;4(3):39-47.
- Leuthner SR, Jones EL. Fetal concerns program: a model for perinatal palliative care. *MCN Am J Matern Child Nurs* Sep/Oct 2007;32(5):272-78.
- MacDonald H. Perinatal care at the threshold of viability. *Pediatrics* Nov 2002;110(5):1024-27.

- Moro T, Kavanaugh K, Okuno-Jones S, Vankleef JA. Neontal end-of-life care: a review of the research literature. *J Perinat Neonatal Nurs* Jul/Sep 2006;20(3):262-73.
- Saflund K, Sjogren B, Wredling R. The role of caregivers after a stillbirth: views and experiences of parents. *Birth* Jun 2004;31(2):132-7.
- Sumner LH, Kavanaugh K, Moro T. Extending palliative care into pregnancy and the immediate newborn period: state of the practice of perinatal palliative care. *J Perinatal Neonatal Nurse* Jan/Mar 2006;20(1):113-6.
- Tully MR. Donating human milk as part of the grieving process. *J Hum Lact* Jun 1999;15(2):149-51.
- Widger K, Picot C. Parents' perceptions of the quality of pediatric and perinatal end-oflife care. *Pediatric Nurse* Jan/Feb 2008;34(1):53-8.