

## *Perinatal Loss*

### CONSENSUS STATEMENT

April 2008

#### POSITION

All Indiana families experiencing perinatal loss deserve compassionate, timely and individualized care. Together, professional and community caregivers can develop supportive environments, systems and resources for women and families during and after a perinatal loss.

#### PURPOSE

The purpose of this document is to identify the needs of women and families experiencing perinatal loss and recommend evidenced-based standards of care and practice wisdom that promote respect for families and positive coping strategies.

#### DEFINITION

For the purposes of this document, perinatal loss is defined as any loss, regardless of reason, from conception through the first year of an infant's life. See Appendix for types of perinatal loss and current Indiana statutes regarding perinatal deaths.

#### INCIDENCE

##### **Nationally**

- 15-50 percent of all pregnancies end early in gestation. (Gilbert & Harmon 2003)
- When considering confirmed pregnancies, approximately 15 percent end in miscarriage. (March of Dimes)
- Approximately 15,000 babies are born each year with conditions that are incompatible with life and die within the first year.
- When stillbirth, newborn death and SIDS are considered, approximately one third of all pregnancies fail to produce a baby that lives past the first year of life.
- Inpatient obstetrical areas can predict 2-4 percent of deliveries more than 20 weeks gestation to end in perinatal loss. (AWHONN 2006)
- 4.7 of every 1000 births die in the first 27 days of life. (Gale & Brooks 2006)
- The death of one or more infants in a multiple pregnancy is 35.4 per 1000 live births, five times the rate of a singleton.
- 20-28 infants per 1000 live births are relinquished to adoptive parents. (Askren & Bloom 1999)

##### **Indiana** (based on 2005 data from the Indiana State Department of Health)

- 10,686 pregnancy terminations
- 475 fetal deaths
- 475 infant deaths within 28 days of life
- 699 infant deaths in the first year of life
- 49 infant deaths from SIDS

Indiana does not document pregnancy losses less than 20 weeks gestation. In line with national trends (i.e. 15 percent of recognized pregnancies) 13,000 pregnancy losses could be added to Indiana's perinatal loss statistics.

In 2004, the last year for which national figures are available, Indiana's fetal death rate (6.1 per 1000 total births) is equivalent to the national rate (6.23 per 1000 total births.) However, Indiana's overall infant mortality rate in 2004 of 8.1 per 1000 live births is considerably higher than the national rate of 6.8 per 1000 live births.

(Indiana State Department of Health and National Vital Statistic Reports, 2004.)

Also, Indiana continues to demonstrate a marked racial/ethnic disparity in infant mortality:

(Indiana State Department of Health, 2005)

- 6.9 deaths per 1000 live births for white infants
- 16.9 deaths per 1000 live births for African American infants
- 8.1 deaths per 1000 live births for Hispanic infants

## RATIONALE

### Consequences for parents

In attempt to decrease emotional distress in families, the medical community offered families little choices in care after a perinatal loss throughout the 1960s, 1970s and early 1980s. Families took direction from the professional community and often did not see, hold or spend time with their deceased infants.

In the early 80's, bereaved parent groups called for change. Professional and lay support organizations evolved with the missions of compassionate care at the time of loss and continued support after the loss. Hospital support programs, caregiver certifications and parent support groups were created. Facilities and communities organized memorial events to honor deceased babies as a way to support families in grief.

Today, it is a standard of care in most obstetrical facilities to provide perinatal grief support in both inpatient and outpatient areas. Many facilities in Indiana also have post-discharge aftercare programs.

Parent support groups continue throughout the state of Indiana, although support via the internet has decreased their utilization. Websites and list-serves answer immediate needs and chat rooms connect the bereaved with those of similar situations and backgrounds.

### Unique components of grief in perinatal loss:

- Most parents and families in childbearing years have yet to experience the death of a loved one. Death is unfamiliar and fearful. (Heustis & Jenkins, 2005)
- The death of an infant goes against what society considers the "normal" life cycle. A parent does not expect to experience the death of his or her child. (Simpson & Creehan, 2001)
- Losing a pregnancy or newborn often involves the grief of unfulfilled hopes and dreams. Some parents make plans for birth and prepare for baby even prior to conception (Lowermilk & Perry, 2004). After the loss, families are left with few tangible memories.
- Demonstrations of grief are directly related to feelings about the pregnancy as well as the death of a child. The gestational age and/or the age of the baby at the time of death are not direct predictors of the intensity of grief families may experience.
- The bond between child and parent is never broken and subsequent children will not replace the lost child (Gemma & Arnold, 2002). Parents and families may need support in finding ways to integrate the life of their deceased child into their family.

**Early pregnancy loss** is marked by society's lack of acknowledgement of a loss of a wanted child. Parents may find little or no support in dealing with their loss. The absence of rituals for early loss denies women the opportunity to mourn among the comfort of others (Int'l J. Psychiatry in Medicine 1999).

- The woman who experiences a **miscarriage** in a hospital or outpatient facility may not be aware of options available for disposition of miscarried remains. Families may not experience opportunities for 'closure', adding to their feelings of loss.
- The woman with an **ectopic pregnancy** may experience concerns for her own well-being and future fertility in addition to the loss of a pregnancy. (Maternity and Women's Health care)
- The woman with a **blighted ovum** may have been told she was "never pregnant", adding confusion to her grief.
- The woman with a **molar pregnancy** may face the loss of the pregnancy as well as future issues of potential cancer risks.
- The woman with a **pregnancy loss after fertility treatment** may experience depression and loss of self-esteem. Maternal age, medical challenges or financial realities may prevent a subsequent pregnancy. Loss of an "instant family" may leave parents disappointed.

## RATIONALE (CONTINUED)

- (synspectrum.com/mourningmultiplied)
- The woman who elects **termination for an unplanned or unwanted pregnancy** may not expect feelings of grief even though it is a normal response of the experience. She may also experience a lack of psychosocial support.
- The woman who elects a **multi-fetal reduction** to reduce risk of complete pregnancy loss may experience guilt and shame about the decision, conflict with beliefs/values and feelings of abandonment in addition to the grief of the loss. (Gilbert & Harmon, 2003). Most felt it was the “right decision” but felt a lack of respect for their loss (Bryan, E. Twin Research 2002.)

Through **prenatal diagnosis**, parents may learn their baby has serious and/or life-ending health conditions and face difficult decisions about the future of the pregnancy. (Schechtman, KB et al, Obstetrics and Gynecology 2002) Families that elect to **terminate a desired pregnancy** experience grief as intense as those with spontaneous second-trimester perinatal loss. Prolonged grief is associated with termination of pregnancy for many women (Korenromp, MJ, et al, Prenatal Diagnosis 2005). Families often find it difficult to discuss their decision secondary to the stigma that surrounds it. In the case of maternal complications, the health of the mother is also a concern for the family. Families **electing to continue the pregnancy** report fear of isolation or abandonment during the pregnancy and at the time of delivery. They also are concerned with the pain and suffering their child may experience once born. The growing perinatal hospital movement offers hospice care throughout the pregnancy and delivery and assures comfort care for baby during his/her life. (Hoeldtke & Calhoun, 2001)

**Stillbirth** often occurs without warning, throwing women and families in the midst of crisis. The mother must still experience labor and delivery, which causes increased distress. There is a general lack of social acknowledgement of life for a baby that was ‘never born.’ Parents often are left without a cause for the death of their baby, even after testing. Anxieties over recurrence can overshadow another pregnancy and may interfere with attachment to future children.

**Multi-fetal pregnancy** carries an increased risk of infant mortality due to preterm delivery, intrauterine growth restriction and life-impacting anomalies. Multiple birth children also have a two-fold risk of SIDS. At the time of loss, parents often must care for surviving multiples and report a compromised ability to bond with survivors due to grief. In the event of multiple simultaneous crises, such as the health of mother or surviving babies, mourning may be delayed. Parents of multiples face hidden losses such as the potential celebrity in raising the original number of children. Parents may find comfort in surviving children but still grieve as intensely as if the lost child was a singleton. Some parents report flashbacks while caring for surviving children. It is not uncommon for grief to be delayed or intensified as compared to singleton grief. (Pector, E. synspectrum.com/protocol/2000.com)

When a baby is admitted to **NICU**, families experience the loss of a “healthy baby”. When their baby dies, that grief is intensified. For medically fragile infants, parents often struggle with issues of foregoing futile care. Parents face the difficult task of giving meaning to a very short life, assigning identity to their baby and redefining their own identity as a parent. (Romesberg, 2004). A plan of care that is in the best interest of both the baby and the family minimizes the long term distress of families after their baby’s death. (Gale & Brooks 2006).

All families should be offered information regarding **after-death testing** in order to find the best answers possible to the questions of ‘why did I miscarry’ and/or ‘why did my baby die?’ Options for testing may be dependent on gestation and/or age of the baby. Parents should be assured that their baby will be treated with dignity and respect during all testing. Options may include:

- Placental exam and pathology
- Pathology of miscarried remains/products of conception
- Autopsy (to be done at local facility or transferred to a Pediatric facility for autopsy by Pediatric Pathologist)
- External clinical exam for newly born infants, performed by Pediatrician, Neonatologist or Medical Geneticist can be an alternative when family declines autopsy
- Chromosome analysis – placental tissue, fetal tissue or blood
- Medical genetics counseling, post loss

## RATIONALE (CONTINUED)

When a baby **dies suddenly at home**, parents are in a state of shock. They imagine ways they could have caused or prevented the death and are eager to assist investigators in finding a cause. Families often report concern about suffering and 'their baby dying alone'; parents may need additional education and support in understanding what happened to their baby.

Mothers that elect **adoption** for their newborn or infant generally cope well with their decision, but some have a difficult time because the child continues to exist. Relinquishing mothers may be at increased risk for long term physical and physiological sequelae due to a prolonged grief response. Many mothers report that seeing their baby after birth and receiving keepsakes was helpful. (Woodger 2000)

**In the weeks, months and years after a perinatal loss**, families report common feelings and challenges:

- Grief impacts physical self as well as emotional and spiritual self. Many parents report physical symptoms such as chest heaviness, aching arms, headaches, alterations in eating and digestion patterns, sleeping difficulties and fatigue. The physicality of grief affects stamina and causes increased stress.
- The loss of hopes and dreams ebbs and flows throughout grief. Parents are unprepared for "grief bursts" related to seemingly unconnected events. Anniversaries and holidays can be difficult times.
- Parents frequently report support from families and friends fell short of expectations and assume that people do not see the death of their baby as an important life event. (Malacrida 2000) Frequently, society allows little time for grieving mothers and even less for the men which can reduce needed support to bereaved parents (Miles & Pelosi).
- Many parents experience other life stressors and losses before, during and after the loss of their pregnancy or baby, causing added hardship and confusion during an already difficult time. (Kavanaugh & Hershberger 2005)
- In general, parents report they rely on their spirituality, seek diversions, try to make sense of their experience and contemplate future pregnancies in coping with their loss. (Kavanaugh & Hershberger, 2005)

The experience of grief is universal, dynamic and individual (Reed, 2003). Each member of the family has their own perspective:

- **Mothers** often feel personally responsible for infertility, miscarriage and infant death. Bereaved mothers tend to be more public and expressive in grief and exhibit higher levels of anxiety and depression for longer periods than bereaved men (Hunfeld & Mourik, 1996; Schwab, 1996). Subsequent pregnancies can be mentally, emotionally and physically taxing. (Robertson, 1998)
- **Fathers'** grief may be acknowledged less frequently, yet men report their role in parenthood as highly important. (McCreight 2004) Responses of fathers may be more variable, especially related to the level of identification with the pregnancy. Men are usually expected to be mother's main support but are often distressed by their partner's grief and feel helpless (Miles and Pelosi). Bereaved men may report grief as a private matter, but grieve with similar intensity as women (Hunfeld & Mourik, 1996). Fathers of stillborn infants report an unfulfilled relationship due to their inability to protect their child and missed opportunities in parenting. (Worth 1997)
- **Couples/partners** may only be able to minimally support one another. The impact of perinatal loss can cause discordant grief experiences (Smorawski, 2001) and risk for further loss through emotional and social isolation or through separation or divorce. (deMontigny, 1999)
- **Children** experience grief in relation to developmental age. (Christ 2000) Children ages 3 – 5 may believe death is temporary while children ages 6 –8 begin to understand that death is permanent. Children ages 9 – 12 are usually logical thinkers and cope best when given concrete information. Early adolescents are generally optimistic and may use denial to address their feelings of grief. Problems not adequately addressed can become sources for added difficulties in adulthood, including psychiatric difficulties (Busch).
- **Grandparents** experience both the death of a grandchild and the suffering of their own child. The emotional pain of both often complicates their grief. As a result grief may be delayed or experienced as "survival guilt" because the death feels "out of order" (Miles &

## RATIONALE (CONTINUED)

- Pelosi).
- Studies on **teen bereaved parents** (Barglow & Istphan, 1973; Stevens-Simon & Kelly, 1996; Wheeler, 1997, Wheeler, 2001) found adolescent mothers mourned similarly to adult bereaved mothers. Socially they reported isolation and feeling “different.” Some view the experience as positive, believing the loss was for the best. They also report a better understanding of the fragility of life and increased feelings of maturity. Some feel a need for a rapid repeat pregnancy. (Wheeler & Austin, 2001; Wheeler & Austin, 1999; Smith, 1999; Horowitz, 1978)

### Role of Providers

Health care professionals have a powerful influence on how families experience and cope with perinatal loss (Cobert-Owen & Kruger, 2001) yet many professionals have difficulty differentiating between supportive care and “fixing” people/situations. (Kowalski, 1993) Caregivers need to encompass **bereavement care** as an attitude rather than a skill, sometimes known as a “companioning presence”. (Heustis & Jenkins, 2005). Bereaved families report they most appreciated health care professionals that listened and validated their loss.

After a loss, parents must find ways to learn to live without their baby. (Laakso & Paunone-Ilonen, 2002) Parents report finding support in a variety of venues:

- Already-established relationships, such as family and friends
- Newly created relationships, such as supportive professionals or other bereaved parents
- Spiritual connections with clergy and places of worship
- Bereaved parent support groups
- Internet connections, such as chat rooms, memorial sites, blogs and bulletin boards
- Reading materials, such as pamphlets, books and internet sites
- Writing, such as journaling, stories and poems
- Events of remembrance, such as memorial services, Walks to Remember, donation programs, etc.

The grief in losing a pregnancy or baby never comes to a resolution. Rather, parent’s grief becomes less all-consuming and the pain of loss lessens over time. Bereaved parents and family find ways to reestablish normal life activities while creating meaning in their experience and ways to remember their deceased baby. (AWHONN, Perinatal Nursing 2006)

Professional and lay caregivers can provide unique opportunities for perinatal loss support through encouragement, teaching, role modeling, counseling, problem-solving etc. Caregivers can also mentor significant others in providing supportive care as well. (Hutti 2005)

Aftercare offers parents and families a vital lifeline. Aftercare programs create organized opportunities for:

- Continued assessment/intervention by experienced grief caregivers (Kavanaugh, 2005)
- Clarification of events that surrounded the loss
- Timely and individualized education about grief and its impact on the family
- Connections to established support systems in their own community
- Mentoring and encouragement in the creation of new support systems needed for coping
- Open lines of communication where parents and families can continue to tell their story and find meaning with people who understand (Kavanaugh and Mao, 2006)

## RECOMMENDATIONS

Perinatal loss can occur in:

- **Inpatient settings**, such as Labor & Delivery, Newborn Intensive Care Units, GYN/ Postpartum Units, or Pediatrics Units.
- **Outpatient settings**, such as an Emergency Rooms, Surgical Suites, Post-Anesthesia/ Recovery, Ultrasound Suites, Clinics or Physician Offices.
- **Home settings**, whether it is an expected or unexpected death.

### Inpatient and outpatient settings

1. Assure the same **standard of care** for all patients of perinatal loss regardless of gestation or cause of death.
2. Create **policies** specific to perinatal loss that serve as guidelines in providing comprehensive

## RECOMMENDATIONS (CONTINUED)

- and compassionate care.
3. Develop an **interdisciplinary team** to support families at time of perinatal loss. An interdisciplinary approach among healthcare staff provides continuity, facilitates the grief process and respects the individual and cultural needs of the family (Ilse, et al, 2002)
  4. Organize **on-going education**, including new employee orientation, for all staff that provides perinatal loss care. Perinatal loss concepts should be included in orientation of new personnel and provided to ancillary units as a reference. (Ilse, et al, 2002) Education should include how to provide sensitive, thoughtful grief care at a time of perinatal loss as well as clinical skills.
  5. Create/adapt **education tools for families** to assist in understanding diagnosis, making decisions and coping with loss. Written information can be a useful reference as patients do not always remember conversations. Written materials alone can lead families to see medical staff as uncaring, so written information is best used as one component of communication. (Geller 2006)
  6. Gather information about up-to-date **local resources** to help meet family's cultural requests.
  7. Offer information and support for families in **disposition** of the body post-death.
  8. Organize a **hospital disposition program** for products of conception that is respectful and culturally sensitive.
  9. Women who present in the **Emergency Department or Outpatient Surgery Unit** for emergent care should be offered options, support and mementos similar to the family experiencing a term gestation infant loss. Staff can follow inpatient protocols and call upon trained support persons in other departments (such as Labor & Delivery or Chaplaincy) for assistance.
  10. All unit standards and staff education should include direction in **culturally-sensitive care**. The health care provider's demonstration of cultural sensitivity further facilitates the grief process by validating the family perception of the "right" way to mourn. (Clements et al. 2003: U.S. Department of Health and Human Services, 2002) By allowing the family to lead the way, care will be specifically tailored and culturally mindful (Heustis and Jenkins, 2004). Culturally-sensitive care includes:
    - Recognizing one's own values and acknowledging that not all patients share the same philosophy in reacting to loss.
    - Developing a knowledge base about a variety of beliefs, religions and cultures that may be encountered during perinatal loss. (AWHONN Lifelines, Vol. 9:4)
    - Asking culturally sensitive questions about what is important to the family and listening to their wishes and concerns.
    - Amassing local resources to meet family's cultural needs and requests.

### Suggested Inpatient Practices

- Discretely flag the patient's door with a marker to signify a loss. (RTS )
- Express condolences to family, such as "I am sorry for your loss."
- Adapt unit environment to meet family's needs for comfort and privacy.
- Provide a safe delivery in a comforting and supportive atmosphere.
- Refer to the baby by name.
- Provide comfort measures for non-viable infant that is born alive such as wrapping in warm blankets, holding, and limiting exams/procedures until after death.
- Provide opportunities for family to say hello and goodbye. Families find it helpful to see and hold their baby. Some families may need additional support in seeing their baby for the first time. (Gilbert & Harmon, 2003)
- If the baby has birth defects, the family may be reluctant to see their baby. Caregivers can facilitate their first experience by focusing on the "perfect" features (hands, feet). Parents should be encouraged to see 'their entire baby' only as they are ready. Photos of the specific anomaly are optional and should be discussed with the family. Lighting, blankets, and props can minimize the appearance of a malformation.
- If the family declines to see their baby after delivery, offer again at a later time, but be sensitive to the family's wishes.
- If baby dies in a facility different than mother's, assure coordination of care between facilities. As soon as mother is physically stable, transfer mother to baby's facility and/or discharge mother as soon as possible so family can be together. If the mother is unable to be moved, consider bringing the baby's body back to the delivering facility after death.

## RECOMMENDATIONS (CONTINUED)

- Siblings, grandparents and other extended family and friends can assist with holding, dressing and bathing the baby, with parent's permission.
- Give written and verbal information regarding mementos, baptisms/blessings, and funeral/burial options. Allow time for discussion and questions on the family's timeframe.
- Create memories. Culturally sensitive photos (35mm and digital), foot/hand prints (ink and/or plaster), clothing, blanket, hat, baby ring or bracelet, lock of hair, baby bands, and crib card, etc. can be included in memory box. (Gilbert & Harmon, 2003)
- If the baby is one of multiples, offer mementos (such as footprints/handprints and photos) together if possible.
- Discuss options of after-death studies with the family, if applicable.
- Assist the physician with genetic studies if ordered.
- Notify Organ Procurement Organization per facility policy for deliveries greater than 20 weeks gestation.
- Offer transfer of mother to a non-OB unit per facility policy and if desired by family. Provide post-partum education verbally and in writing. Postpartum education should include written information on grief support, bereavement aftercare and self-care at home. Include hospital contact numbers.
- Discuss options for hospital disposition, if applicable, and/or private disposition (i.e. burial or cremation.) Families may need guidance and resources to make disposition arrangements.

### Suggested Outpatient Practices

- Mark chart to alert staff of perinatal loss.
- Assess patient/family's perception of loss. Asking questions like "What was it like for you when you heard the bad news about this pregnancy?" will help guide the level of support to be offered.
- Offer a memory packet for ultrasound pictures, a positive pregnancy test, etc. This may help acknowledge the pregnancy and give the family something to physically hold.
- Offer information in verbal and written form about pregnancy loss, perinatal grief and care as part of post-discharge instructions.
- Discuss disposition options and allow the family to choose what best meets their needs.
- Explore mother's/family's interest in receiving genetic testing and/or genetic counseling post loss.
- In cases where surgical intervention is required, assure supportive bereavement care is added to post-surgical standards of care.
- Offer information/support regarding future fertility in addition to grief care teaching. (Maternity and Women's Health care, Chapter 31)
- For molar pregnancies, offer guidance and education about prognosis with treatment, recovery, and future fertility issues.
- Offer to access hospital and community resources (trained nurses, bereavement programs, chaplaincy, social work, peer support groups, etc.) for support after discharge.

### Home Settings

1. First responder teams (i.e., law enforcement, fire/ambulance personnel, hospital emergency department staff, investigation personnel and coroners/medical examiners) should follow protocol consistent with Sudden Unexpected Infant Death guidelines from the Centers for Disease Control and Prevention ([www.cdc.gov/SIDS/SUID.htm](http://www.cdc.gov/SIDS/SUID.htm)).
2. A thorough investigation should be done, avoiding assumptions about the possible cause of death. At the scene, first responders should be non-accusatory, treating the home as a death scene and not a crime scene. Families appreciate sensitive and supportive first responders that are willing to help them say goodbye under such traumatic conditions. (Journal of American Academy of Pediatrics, 2001)
3. In cases of unexpected death, autopsy is mandated by law for children under 3 years of age. In situations that mandate Coroner investigations, decisions regarding post-mortem testing are deferred to the Coroner. Families should be informed of testing that will be done
4. Call the baby by name in all discussions.
5. Offer parents time to see, hold and be with their baby before transporting body, if possible.
6. Designate a person, either within the first responder team, clergy or family member/friend, who can act as a liaison, provide immediate support, escort family to the hospital if needed and notify support systems.

## RECOMMENDATIONS (CONTINUED)

7. Complete a thorough assessment including the position of infant, marks on the body, body temperature and rigor, type of bed and any defects, amount and position of clothing and bedding, room temperature, type of ventilation/heating and reaction of the caregivers. SIDS diagnosis is exclusionary and requires a death scene investigation, clinical history and complete autopsy.
8. Inform family verbally and in writing about 'the next steps', especially if the investigation will be under the supervision of the Coroner's Office. Assure families have access phone numbers to investigators if needed.
9. Offer family written information about grief and local resources or refer to organizations that offer grief support if no written information available at the scene.
10. Assure connections to support systems, such as crisis intervention teams, funeral-planning, breast feeding cessation, and caring for grieving children.

### **Aftercare for Families**

Hospital facilities and community groups can work together to provide a multi-disciplinary and multi-faceted support system for families. (Gilbert & Harmon, 2003); (Lowermilk & Perry, 2004).

### **Suggested Aftercare Program Practices:**

- Provide access to supportive people. Families should know who to call when they need help.
- Follow-up with families by phone, mail or in person within one week of loss and again several weeks later. Follow-up consultations can also be made in conjunction with the mother's postpartum appointment. (Kavanaugh & Mao, 2006) Many programs will stay in contact with families for the first year.
- Provide added options for support during special times such as birthdays, due dates, holidays, anniversaries, etc.
- Provide oral and written information that outlines 'normal' grief, caring for self while grieving and resources in the community.
- Provide families access to support materials such as books, internet sites, etc.
- Facilitate connections to peer support through parent support meetings or informal connections with other grieving parents.
- Develop a plan for parents experiencing complicated grief. Referral to local mental health agencies may be necessary in some situations. (Gilbert & Harmon, 2003)
- Organize opportunities for ceremonies of remembrance that are community-based and/or facility-based.
- Facilitate connections for subsequent pregnancy support.

# Resources

## ► State-Wide Resources for Families

**Neofight** [www.neofight.org](http://www.neofight.org) or (317) 446-3013

One-on-one connections for families experiencing a perinatal crisis with a trained veteran parent. Also provides Listener Training classes, speaker panels, printed materials and a 24 hour listening line.

## ► National Resources for Families

**Now I Lay Me Down to Sleep** [www.nowilaymedowntosleep.org](http://www.nowilaymedowntosleep.org)

A network of professional photographers across the country offering private, sensitive portrait sessions for families at a hospital or hospice location. Services are offered at no charge to families.

**SHARE Pregnancy and Infant Loss Support** [www.nationalshareoffice.com](http://www.nationalshareoffice.com)

St. Joseph Health Center, 300 First Capital Drive St. Charles, MO 63301  
636-947-6164 or 800-821-6819

Grief support at the time of/or following the death of a baby. Bimonthly newsletter and national list of support groups.

**Alliance of Grandparents, a Support in Tragedy (AGAST)** <http://www.agast.org/>

For grandparents experiencing the trauma, and grief after the loss of a grandchild.

**Baby Steps** <http://www.babysteps.com>

General support for the loss of a child.

**Bereaved Parents of the USA (BPUSA)** [www.bereavedparentsusa.org](http://www.bereavedparentsusa.org)

Support for bereaved parents, siblings, and grandparents. HAS SPANISH RESOURCES.

**Center for Loss in Multiple Birth** [www.climb-support.org](http://www.climb-support.org)

Support for death of one or more twins or higher multiples at any time from conception through birth, infancy and childhood.

**Grief Watch** <http://www.griefwatch.com>

Spiritual, emotional and other support through bereavement resources, memorial items and links.

**Griefnet** [www.griefnet.org](http://www.griefnet.org)

E-mail support groups for bereaved parents, siblings, and grandparents. Also comprehensive resource lists and a sister Web site for bereaved children, KIDSAID <http://www.kidsaid.com>.

**Ectopic Pregnancy Trust** <http://www.ectopic.org>

Info and support for women with ectopic pregnancies.

**Mommies Enduring Neonatal Death (MEND)** <http://www.mend.org>

Christian support for those who have lost a child due to miscarriage, stillbirth or early infant death. Includes support groups, quarterly newsletter.

**Mothers in Support and Sympathy (MISS)** [www.missfoundation.org](http://www.missfoundation.org)

Immediate and ongoing support to grieving families and caregivers. INCLUDES SPANISH RESOURCES

**Resolve: The National Infertility Association** <http://www.resolve.org>

Education, advocacy and support for women and men facing infertility. Includes a help line, physician referral service, and monthly magazine.

## ► Special Resources for SIDS

**First Candle/SIDS Alliance** [www.firstcandle.org](http://www.firstcandle.org)

1-800-221-7437 or 1-800-638-7437

Family support, National SIDS & Infant Death Program Support Center. 24 hour bilingual support crisis line. HAS SPANISH RESOURCES

**CJ Foundation for SIDS** [www.cjsids.com](http://www.cjsids.com)

30 Prospect Avenue, Hackensack, NJ 07601 201-996-5111

National voluntary health organization dedicated to specific needs of the SIDS community through funding SIDS research and support services.

► **Special Resources for Families in Prenatal Decision-making**

**A Heartbreaking Choice** [www.aheartbreakingchoice.com](http://www.aheartbreakingchoice.com)

Information/ support to parents who have interrupted their pregnancies after prenatal diagnosis revealed severe fetal anomalies.

**Carrying to Term** [www.geocities.com/tabris02](http://www.geocities.com/tabris02)

Support for parents who continue a pregnancy after prenatal diagnosis.

**National Organization of Rare Disorders** [www.rarediseases.org](http://www.rarediseases.org)

Information on rare diseases and database of support organizations.

► **Resources for Caregivers**

**Indiana Perinatal Network** [www.indianaperinatal.org](http://www.indianaperinatal.org) or 1-800-433-0746

Statewide network that provides education, advocacy and resources for all families and babies in Indiana.

**Gundersen Lutheran Bereavement Services** [www.bereavementservices.org](http://www.bereavementservices.org)

1910 South Avenue, La Crosse, WI 54601, 1-800-362-9567 ext. 4747

Professional training and educational resources for bereavement care.

**WiSSP: Wisconsin Stillbirth Service Program** [www.wisc.edu/wissp](http://www.wisc.edu/wissp)

Resources for professionals to help to address questions surrounding a stillbirth. Newsletter and list of publications for medical professionals.

► **Internet Resources: written materials for caregivers and families**

**A Place to Remember** [www.aplacetoremember.com](http://www.aplacetoremember.com)

Resources for infant loss, including books, announcements, memory boxes, and materials for bereaved families.

**Centering Corporation** [www.centeringcorp.com](http://www.centeringcorp.com)

Resources for bereaved families and siblings.

**Perinatal Loss** [www.griefwatch.com/pl/default.htm](http://www.griefwatch.com/pl/default.htm)

Resources for bereaved families and caregivers. Site/resources created by, for, or in memory of someone who has gone through perinatal loss.

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# Appendix

## ► Types of Perinatal Loss

### Prior to the 20th week of pregnancy:

- Blighted Ovum –Fertilized ovum that ceases to develop at an early stage of pregnancy.
- Molar Pregnancy/Hydatidiform mole – Abnormal cluster of cells that develop post-fertilization instead of a normal embryo. Relatively rare condition. May trigger a positive pregnancy test. Some cases may become cancerous.
- Ectopic Pregnancy – Implantation of fertilized egg outside of the uterus, most commonly in the fallopian tube.
- Miscarriage/spontaneous abortion – Delivery of embryo or fetus without signs of life at 20.0 weeks or less gestation.
- Medical Termination/medical abortion – Termination of pregnancy based upon diagnosis of maternal and/or fetal complications.
- Elective Termination/ elective abortion– Termination of pregnancy without diagnosis of maternal or fetal complication.
- Multi- fetal reduction/selective abortion -Termination of one or more fetuses in a multi-fetal pregnancy based upon maternal health risk and/or to optimize fetal outcome.

### 20.1 or more weeks of pregnancy

- Stillbirth – Delivery of fetus without signs of life at 20.1 or more weeks gestation; also referred as intrauterine fetal demise (IUFD).

### Newborn period

- Neonatal Death – Death of live born infant within 28 days of birth; includes all babies born with signs of life per Indiana Law, regardless of gestation.
- Adoption – Voluntary release of a child to non-biological parents, with legal confirmation.

### 1st year of life

- Infant Death, Explained – Death of an infant through any event, where the cause is known.
- Infant Death, Unexplained– Death of an infant that remains unexplained after a thorough investigation is completed.

## ► State of Indiana Definitions ([www.in.gov/legislative/ic/code](http://www.in.gov/legislative/ic/code))

- **Viability** IC 16-18-2-365. The ability of a fetus to live outside the mother's womb. No parameters by gestation are included.
- **Live birth** IC 16-18-2-205. Birth of a child who shows evidence of life after the child is entirely outside the mother. Evidence of life includes breathing or gasping, heart action including pulsation of the umbilical cord, or voluntary movement of the muscles. This would include any fetus REGARDLESS OF GESTATION or FETAL WEIGHT. Any fetus born alive shall be treated as a person under the law, and a birth certificate shall be issued certifying the child's birth event though the child may subsequently die, in which event a death certificate shall be issued. IC16-34-2-3. The disposition of any live born baby must be handled by a private funeral service (i.e. privately buried or cremated.)
- **Stillbirth** IC16-18-2-340. Birth after twenty weeks gestation that is not a live birth. That is, no evidence of breathing or gasping, heart actions including pulsation of the umbilical cord, or voluntary movement of the muscles. A Certificate of Fetal Death must be completed and filed with the local health officer. (IC16-37-3-3). The disposition of any stillborn baby must be handled by a private funeral service (i.e. privately buried or cremated.)
- **Products of conception.** Delivery of an embryo or fetus less than 20 weeks gestation that shows no evidence of life when entirely outside the mother. Products of conceptions are considered obstetrical waste and may be disposed of accordingly. Fetuses less than 20 weeks can be buried or cremated, per parent's wishes, but is not required by law.
- **Termination of Pregnancy** IC 16-34-2. Outlines care required by state facilities for termination of a pregnancy.
- **Mandatory autopsy in cases of unexpected death** IC 36-2-14-6. County coroner must perform autopsy in unexpected death of children 1 week – 3 years old.

# Appendix

## Indiana State Department of Health Infant and Fetal Mortality Data 2005

|          | Births | Infant Deaths |                   | Neonatal Deaths |      | Post-Neonatal Deaths |      |
|----------|--------|---------------|-------------------|-----------------|------|----------------------|------|
|          |        | Number        | Rate <sup>1</sup> | Number          | Rate | Number               | Rate |
| Total    | 87,088 | 699           | 8.0               | 475             | 5.5  | 224                  | 2.6  |
| White    | 75,464 | 519           | 6.9               | 343             | 4.5  | 176                  | 2.3  |
| Black    | 9,820  | 166           | 16.9              | 123             | 12.4 | 43                   | 4.4  |
| Hispanic | 8,026  | 65            | 8.1               | 49              | 6.1  | 16                   | **   |
| Other    | 1,804  | 14            | **                | 9               | **   | 5                    | **   |

<http://www.in.gov/isdh/dataandstats/mortality/2005/table08/tbl08.htm#IDX13>

\*\* The number is less than 20 and the rate is unstable.

1-Rate is per 1,000 births.

| Fetal Deaths <sup>2</sup> |        |                   |
|---------------------------|--------|-------------------|
|                           | Number | Rate <sup>3</sup> |
| Total                     | 475    | 5.4               |
| White                     | 343    | 4.5               |
| Black                     | 91     | 9.2               |
| Hispanic                  | 54     | 6.7               |
| Other                     | 41     | 22.2              |

<http://www.in.gov/isdh/dataandstats/mortality/2005/table10/tbl10a-14.htm>

2-Fetal Deaths are defined as deaths prior to completed delivery of a fetus of 20 or more weeks gestation.

3-Fetal Death Rate equals Fetal Deaths divided by (Fetal Deaths plus Live Births) multiplied by 1,000