

## Perinatal Loss: Resources for Families

Listed below are a host of resources to support parents, families and children through difficult times of loss and grief.

### Support Groups and Resources

- **Share: Pregnancy and Infant Loss Support** [www.nationalshare.org](http://www.nationalshare.org)  
Provides support and information for families who have experienced the death of a baby through early pregnancy loss, stillbirth, or in the first few months of life.
- **The MISS Foundation** [www.missfoundation.org](http://www.missfoundation.org)  
Provides support and resources to families after the death of a child from any cause. Also participates in legislative and advocacy issues, community engagement and volunteerism, and culturally competent, multidisciplinary, education opportunities. Provides online support groups, listings of local in-person support opportunities, and a regular newsletter for parents. The Foundation is committed to providing long-term support to families after a child's death.
- **Now I Lay Me Down to Sleep** [www.nowilaymedowntosleep.org](http://www.nowilaymedowntosleep.org)  
Provides infant remembrance photography. A national network of photographers who volunteer their services to families experiencing neonatal death. This service is provided free of charge.
- The mission of **Courageous Parents Network** is to support parents and families of children living with life-limiting illness with the tools they need as they adjust to the prognosis and then when they contemplate their child's transition to end-of-life. They do this by providing parents with coping resources around Anticipatory Grief, Bereavement and all the Living in-between; providing parents with a framework within which to think about the tough questions, including end-of-life; advocating for pediatric palliative care; and educating professionals around the needs and experiences of parents caring for these children. At the heart of *Courageous Parents Network* are the parents themselves: parents sharing – through video – their experiences and feelings, speaking frankly about intimate challenges and moments in caring for their sick child including through the end-of-life. <http://courageousparentsnetwork.org/>
- **Communication Counts: A Toolkit for Families Experiencing Childhood Illness** is a practical, innovative, and comprehensive resource to support families with a school-age child living with life-threatening illness. *Communication Counts* offers three toolkits, tailored to the stage of the illness the child is experiencing: 1) *Supporting Your Child and Family During Diagnosis and Treatment*; 2) *Supporting Your Child and Family While Transitioning to Supportive Care*; and 3) *Supporting Your Family Through Bereavement*. All three *Communication Counts* toolkits are available for **download** and use by individual families. <http://shop.danya.com>
- **PLIDA: Pregnancy Loss and Infant Death Alliance** [www.plida.org](http://www.plida.org)  
Promotes awareness about the emotional aspects of perinatal loss and bereavement, advocates for comprehensive and compassionate care for families, and offers information and support for medical providers who work with bereaved families.
- **Perinatal Hospice** [www.perinatalhospice.org](http://www.perinatalhospice.org)

Offers general information and support for families, caregivers, and providers related to perinatal hospice. Provides information and links to order books related to perinatal hospice and bereavement.

- **Be Not Afraid** (\*\* Christian affiliation) [www.benotafraid.net](http://www.benotafraid.net)  
Serves as an online network of parents and medical providers who have experienced and/or worked with families who have chosen to continue a pregnancy after receiving a poor prenatal diagnosis. Includes personal stories, articles, and information about specific conditions and diagnoses.
- [www.honoredbabies.org](http://www.honoredbabies.org) Serves as a support and resource organization for women whose babies have died from miscarriage, ectopic pregnancy, pregnancy termination, stillbirth, neonatal death, or infant death. Allows parents to post memorials for their children.
- **AMEND: Aiding Mothers and Fathers Experiencing Neonatal Death** [www.amendgroup.com](http://www.amendgroup.com)  
Offers a free counseling service to parents who have experienced the loss of an infant through miscarriage, stillbirth, or neonatal death. The main purpose of AMEND is to offer support and encouragement to parents having a normal grief reaction to the loss of their baby.
- **CLIMB: Center for Loss in Multiple Birth** [www.climb-support.org](http://www.climb-support.org)  
Provides parent-to-parent support for families who have experienced the death of one or more twins or higher multiple birth children at any time from conception through birth, infancy and early childhood. Also assists extended families, caregivers, twins and multiples organizations and others who are seeking to understand and support the needs of parents with a multiple birth loss. Promotes awareness and education around the needs of bereaved families and the importance of prevention of multiple birth loss.
- **Caring Bridge** [www.caringbridge.org](http://www.caringbridge.org)  
Provides free, personalized, easy-to-use websites for families experiencing a medical crisis. Friends and family can check in and get updates as well as leave messages of support. Families also use their websites as a legacy for babies who die.
- **My Forever Child** [www.myforeverchild.com](http://www.myforeverchild.com)  
Online store offering child loss keepsakes. Creates unique memorial keepsakes, remembrance jewelry and sympathy gifts to comfort those touched by the loss of a child, through miscarriage, stillbirth, pregnancy and infant loss, newborn, toddler, older child, teen and adult death.
- **Compassionate Passages** [www.compassionatepassages.org](http://www.compassionatepassages.org)  
Provides advocacy, education, and research to assist families, health care providers, and the community in being supportive during and after the death of a child.
- **Grief Watch** [www.griefwatch.com/pl/default.htm](http://www.griefwatch.com/pl/default.htm)  
Publishes, creates, and distributes written materials, including books for siblings. The Grief Watch site provides bereavement resources, memorial products, and educational tools.

#### **Websites About Specific Diagnoses**

- **Antenatal Results and Choices** [www.arc-uk.org](http://www.arc-uk.org)

Provides resources for families that have received a diagnosis that is fatal or likely to be fatal. Resources include information about prenatal tests and diagnoses, lists of questions for parents to ask medical providers, and support opportunities for parents.

- **Anencephaly Support Foundation** (\*\*Christian affiliation) [www.asfhelp.com](http://www.asfhelp.com)
- **Congenital Diaphragmatic Hernia** [www.cdhsupport.org](http://www.cdhsupport.org)
- **CHERUBS**- The Association of Congenital Diaphragmatic Hernia Research, Advocacy, and Support.
- **Trisomy 18** [www.trisomy18.org](http://www.trisomy18.org)
- **Congenital Heart Defects** [www.congenitalheartdefects.com](http://www.congenitalheartdefects.com)
- **Potter's Syndrome (Bilateral Renal Agenesis)** <http://www.potterssyndrome.org>

#### **Sudden Infant Death Syndrome**

- **CJ Foundation for SIDS** [www.CJsids.com](http://www.CJsids.com)
- **Compassionate Friends** [www.compassionatefriends.org](http://www.compassionatefriends.org)
- **First Candle** [www.firstcandle.com](http://www.firstcandle.com)
- **National SIDS/Infant Death Resource Center** [www.sidscenter.org](http://www.sidscenter.org)
- **NCCC-SIDS (National Center for Cultural Competence)**  
[www11.georgetown.edu/research/gucchd/nccc/projects/sids](http://www11.georgetown.edu/research/gucchd/nccc/projects/sids)
- **Project Impact** [www.sidsprojectimpact.com](http://www.sidsprojectimpact.com)
- **SIDS Network** [www.sids-network.org](http://www.sids-network.org)

#### **Genetic Disease Information**

- Searchable database of genetic condition [http://www.geneticalliance.org/ws\\_display.asp?filter=home](http://www.geneticalliance.org/ws_display.asp?filter=home)

#### **Books**

- ***Waiting with Gabriel: A Story of Cherishing a Baby's Brief Life***, by Amy Kuebelbeck [www.waitingwithgabriel.com](http://www.waitingwithgabriel.com)
- ***Stillbirth, Yet Still Born***, by Deborah Davis [www.perinatalhospice.org/our\\_books.html](http://www.perinatalhospice.org/our_books.html)