Helpful Groups

~ Helpful Organizations ~

Links and contacts are provided for information only and are not endorsed by SOFT.

Found a Broken Link? Contact the [Website Content Manager](#) to report an inactive link.

♥ Caring Bridge  A protected site for connecting family and friends during a health event.

♥ The Little Angels Foundation:  This non-profit foundation provides caskets free of charge to families who have lost a child. They ask families to connect with them through their child’s funeral home. They will speak directly to parents but prefer a 3rd party contact. Some states such as California have laws that will not allow caskets to be shipped in from other states. A funeral home director will likely know if there is such a law in your state. Located in Louisiana, time can be an issue for out of state delivery and at present the builder is one man. It takes 24-48 hours to complete a casket. If the size needed is in stock, 2-3 days’ notice is needed but for out of state delivery 5-7 days is best.
❤ Molly Bear Foundation. This foundation was created in loving memory of Molly by her parents. “The goal of the Molly Bear Foundation is to provide supplemental financial assistance to families raising children with Trisomy 18. Unfortunately Molly Bear will not be able to support every family in need, but we will do our best” (Quote from Website).

❤ National Dissemination Center for Children with Disabilities (NICHCY) is a national information center that provides information on disabilities and disability related issues such as early intervention and special education, focusing on children and youth, birth to age 22. Information is in English or Spanish.

❤ Pacer Center Pacer Center is a parent training and information center for families of children from birth through 21 years located in Minneapolis that serves families across the nation as well as Minnesota. EZ-AT-book-2011-final.pdf is a booklet which can be ordered or downloaded from this site, and has practical ideas to help the disabled child (birth – three year old) but many ideas are applicable to kids of all ages. Be sure to also check out Assistive Technology at this site.

❤ Tracking Rare Incidence Syndromes (TRIS): The TRIS project provides a means to change perceptions about children with rare trisomy conditions. Through data from TRIS Surveys, new
information is available about long-term survival, positive surgical outcomes and achievement of developmental milestones such as using gestures and vocalizations to communicate, walking (with or without assistance) and interacting with family members. A combined total of 860 surveys representing children and adults with rare incidence conditions such as trisomy 18, trisomy 13 and trisomy 9 mosaic were completed as of 10/31/16. 58.3% of children were at least 2 months of age or greater.

A total of 1007 children and adults are enrolled in the project; many are SOFT members. Your participation is welcomed and encouraged. Contact Debbie Bruns, Ph.D., Southern Illinois University, Carbondale, IL at dabruns@siu.edu or go to the project enrollment page located at http://tris.siu.edu/survey/form/PreEnroll.php

♥ The Compassionate Friends (TCF) is a national non-profit organization which offers grief support after the death of a child of any age. Local chapters of TCF may be available in some areas.

♥ Mothers in Sympathy and Support (MISS) Foundation is an international on-line support for grieving families. Random Act of Kindness Day done in memory of my beautiful child is an annual MISS event.

♥ Alexandra’s House is a charitable perinatal
hospice and infant refuge.

♥ **Be Not Afraid (BNA)** BNA is a private, non-profit corporation whose mission is to provide comprehensive, practical and peer-based support to parents experiencing a prenatal diagnosis and carrying to term. In addition, BNA encourages development of new services so more parents find support at diagnosis by offering training, consulting and technical assistance as well as materials to other organizations and individuals committed to service development.

♥ **Perinatal Hospice/Palliative Care Programs:** Provides a list of Perinatal hospice/palliative care programs and support in the USA and Internationally. These programs are a relatively new concept of care for parents who choose to continue a pregnancy after learning their expected baby has a life-limiting diagnosis.

♥ **Prenatal Partners for Life** was founded by Mary Kellett, mother of Peter who had trisomy 18. This organization provides support information and encouragement for carrying to term with an adverse prenatal diagnosis and support for raising your child with special needs after birth.

♥ **Now I Lay Me Down to Sleep** foundation (NILMDTS) administers a network of almost 6,000 volunteer photographers in the United States and twenty-five international countries. At a
family’s request, a NILMDTS Affiliated Photographer will come to your hospital or hospice location and conduct a sensitive and private portrait session. The portraits are then professionally retouched and presented to the families on an archival DVD or CD that can be used to print portraits of their cherished baby. Our entire network of affiliated photographers graciously donates their time and talents to our families and we are proud to be able to offer our services at no cost. Video of Trisomy Children

♥ Portraits by Dana: Specializes in gently drawn pencil portraits for families who have suffered an early loss. Whether you have photos of your child or not, a peaceful remembrance portrait can be created and customized to your wishes. I believe all ‘life’ is precious and should be remembered and recognized – no matter how short, no matter how small.