Texas Parent to Parent
NICU
Statewide Resource Information

Texas Parent to Parent
(512) 458-8600
(866) 896-6001
www.txp2p.org

A statewide non-profit developed for parents by parents: provides parent to parent matches, emotional support and information for parents of babies who spent time in a Neonatal Intensive Care Unit.

Mission:

Texas Parent to Parent supports children with disabilities, chronic illness, and other special healthcare needs by empowering their parents to be advocates for them through peer support, resource referral and public awareness.

Services

2-1-1 Texas

2-1-1 Texas provides information on and access to Medicaid, Food Stamps, Temporary Assistance for Needy Families (TANF), Children’s Health Insurance, nursing home care and other services. When callers dial 2-1-1, they are connected to area information centers in their region. 2-1-1 is a partnership with the Texas Health and Human Services Commission and Area Information Centers statewide. The goal is to be a “one stop” comprehensive, confidential information and community resource.

Texas Early Hearing Detection and Intervention (TEHDI)
(800) 252-8023
http://www.dshs.state.tx.us/tehdi/Audiology-Services-Home.aspx

The TEHDI program is designed to identify newborns with potential hearing loss, do further testing to define the degree and type of hearing loss, fit them with hearing aids if appropriate, and enroll them in intervention services prior to six months of age.

Texas Department of State Health Services, Women, Infants and Children Program (WIC)
(800) 942-3678
http://www.dshs.state.tx.us/wichd/

The Special Supplemental Nutrition Program for Women, Infant and Children, known as WIC, is a nutrition program that helps pregnant women, new mothers, and young children eat well, learn about nutrition, and stay healthy. WIC provides nutrition education and counseling, nutritious foods, breastfeeding information and help accessing health care to low-income women, infants, and children.
Services, continued

WIC’s Breastmilk-Every Ounce Counts - Website with a link to identify community resources to support breastfeeding including WIC clinics and Milk banks. Under the “Every Ounce Counts Campaign” link you can create your own birth announcement; there is also a link to “Sing to Me” – A Lullaby Album which includes songs by Texas musicians focused on mothers and babies and it includes a downloadable file of all the songs. http://www.breastmilkcounts.com/resources.html

Texas WIC Breast Pump Program
(800) 942-3678
www.texaswic.org

All WIC moms with a premature infant or who are separated from their infant due to medical reasons are eligible to receive (on loan) a hospital grade pump. Women not enrolled in WIC may qualify based on household income. Contact a local WIC office for more information.

Human Milk Banking Association of North America
https://www.hmbana.org/

This website provides information on the location of affiliated milk banks, the history of milk banking, answers to frequently asked questions (FAQ), how donor milk is processed and how to donate milk. There are also links to order publications and other resources. The Mother’s Milk Bank Austin, http://www.milkbank.org/ and the Mother’s Milk Bank of North Texas, http://www.texasmilkbank.org/ are both HMBA affiliates and their websites are helpful in locating milk drop off locations around the state.

Department of Assistive and Rehabilitative Services (DARS)
ECI (Early Childhood Intervention)
(800) 628-5115
(866) 581-9328 TTY
www.dars.state.tx.us/ecis/

Services for children, birth to 3-years-old, who have a developmental delay or disability. Services are provided in the home and community. ECI uses a family-centered team approach to develop a plan for the family to help the child grow and learn. Team members come from a variety of professions including Early Intervention Specialists, Nurses, Registered Dietitians, Therapists and Social Workers. There is no cost to the family for an intervention. Services are provided on a sliding scale but no family will be denied services due to an inability to pay. ECI produces a range of materials helpful to families, including a Resource Guide describing programs, services and resources for families.
Services, continued

Division for Blind Services (DARS)
Formerly Texas Commission for the Blind
(800) 628-5115
(866) 581-9328 TTY
www.dars.state.tx.us/dbs/

The Blind Children’s Vocational and Discovery Program provides information and support to help families who have a child that is blind or visually impaired. A Blind Children’s Program Specialist – an expert in providing services to children with visual impairments – works with each child and family to create a Family Service Plan. Their focus is on restoring vision and reducing dependency.

Office of Deaf and Hard of Hearing Services
Formerly Texas Commission for the Deaf
(800) 628-5115
(866) 581-9328 TTY
www.dars.state.tx.us/dhhs/index.shtml

Information and referral for persons that are deaf/hard of hearing, their family members and their service providers. Provides financial assistance for hearing aids, assists with local interpreter services and sponsor summer camps for children and youth that are deaf/hard of hearing. Hearing Loss Resource Specialists (HLRS) provide services to persons with hearing loss.

Department of Aging and Disability Services (DADS)
Formerly MHMR (Mental Health & Mental Retardation)
(800) 458-9858
www.dads.state.tx.us

Provides some services and financial programs like respite money, In-Home and Family Support program and Medicaid waiver programs

InfantSee
http://www.infantsee.org/x3421.xml 1-888-396-3937

InfantSEE®, Through this program optometrists provide a one-time, comprehensive eye assessment to infants in their first year of life, offering early detection of potential eye and vision problems at no cost regardless of income. A vision assessment is recommended for all infants age 6-12 months and is especially important for premature babies. The Infant SEE website includes information for parents about vision milestones and activities to develop vision, eye health terms and a locater to find optometrist providers for the InfantSee program.
Internet Support and Information Related to Premature Babies

La Leche League
http://www.llli.org/
(800) 525-3243

Their Mission is to help mothers worldwide to breastfeed through mother-to-mother support, encouragement, information, and education, and to promote a better understanding of breastfeeding as an important element in the healthy development of the baby and mother.

Their website includes links to helpful resources, includes a forum for breastfeeding a preemie and downloadable podcasts on a variety of topics.

National Organization of Mothers of Twins Clubs
http://www.nomotc.org/

The National Organization of Mothers of Twins Clubs, Inc. is a non-profit organization dedicated to supporting families of multiple birth children through education, research, and networking.

March of Dimes-NICU
http://www.marchofdimes.com/baby/inthenicu.html

Information for parents of babies in the NICU. Includes a reference guide with NICU related terms, common tests, typical questions and answers, a list of NICU staff and their roles, tips for surviving the NICU experience, how to advocate for your baby and information about how to make the transition from the hospital to home. This website also includes a mechanism for submitting questions.

March of Dimes hosts an on-line community featuring, sharing your story, discussion of topics related to the NICU and a mechanism for blogging about your experience. http://www.shareyourstory.org/webx/Share%20Home/

Inspire-Preemie Support Community
http://www.inspire.com/groups/preemie/discussions

Inspire connects patients, families, friends, caregivers, and health professionals for health and wellness support. The Preemie Support Community is one of their online discussion and support networks.

Preemie Voices

Information to help families navigate the journey of prematurity. Website contains fifteen documents focusing on topics of interest to families of premature babies, for example, 5 Reasons for Hospitalization, Preemie Glossary, Milestones, Special Needs, Keeping Baby Healthy. Most materials are available in English and Spanish. The material is developed by a division of MedImmune, LLC focused on advocacy for
Internet Resources, continued

preemies. The website contains information on national and legislative issues impacting preemies, as well as many helpful resources targeted for families.

**Preemies Today**  
http://www.preemiestoday.org/index.php  
A national preemies support network, is a non-profit organization founded by parents of preemies. Resources include monthly on-line chats and listservs that allow families to connect based on their child’s age, English and Spanish newsletter and resource information (including downloads on feeding and sensory development).

**PreemieCare**  
http://www.preemiecare.org/index.htm  
PreemieCare is a division of MOST (Mothers of Supertwins), Inc. a non-profit parenting organization that provides information, education, support and additional resources for families of multiples. PreemieCare has a special focus on RSV awareness and prevention. Issues such as breastfeeding preemies, parenting in the NICU, early intervention are also addressed by PreemieCare, as are networking opportunities for preemie support groups.

**Preemie Prints**  
www.preemieprints.org  
Preemie Prints is a Texas 501(c)3 nonprofit organization dedicated to sharing hope with families experiencing the difficulties of life in a neonatal intensive care unit with a premature or sick baby through information, photography, gift bags, support, and prayer. Preemie Prints offers face to face, online and group meetings in the Brazos Valley and Fort Bend County area, Houston, Waco and Temple.

**American Academy of Pediatrics/ About HealthyChildren.org**  
http://www.healthychildren.org/english/ages-stages/Pages/default.aspx  
HealthyChildren.org is a parenting website backed by the American Academy of Pediatrics. It provides general information related to child health and guidance on parenting issues. Covered topics include ages and stages information (including a section on preemies that addresses topics about life in the NICU and making the transition home), immunizations and a wide variety of health, nutrition, wellness and current pediatric health issues. Users are able to register and customize receipt of information according to age and interest. There is an “Ask a Pediatrician” tool that allows users to browse a database of current questions and submit questions to be answered.
Internet Resources, continued

Zero to Three
http://www.zerotothree.org/
ZERO TO THREE is a national nonprofit organization that informs, trains and supports professionals, policy leaders and parents in their efforts to improve the lives of infants and toddlers. Includes resources for families related to solving parenting issues and guidance on nurturing a child’s growth and learning. The focus is on general parenting issues and topics and is an excellent resource on the early development of a child.

National Perinatal Association
http://www.nationalperinatal.org/index.php  Toll Free: (888) 971-3295
A multidisciplinary organization dedicated to promoting the health and well being of mothers and infants. The National Perinatal Association (NPA) website contains links to information about its annual conference, position statements on a variety of topics (e.g. NICU Developmental Care, Breastfeeding, Substance Abuse in Pregnancy), discussion forums and historical conference calls and webinars on NICU related topics. The Family Advocacy Network (FAN) page contains a link to state support groups and historical network topical conference calls.

CLIMB, The Center for Loss in Multiple Birth, Inc.
http://www.climb-support.org
This website was founded by parents in the United States, Australia, Canada and New Zealand to provide support to parents of twins and multiples who have experienced a loss at any time from conception through childhood. The mission of the group is to ensure no one feels alone when dealing with their loss and to offer information written by parents. CLIMB also offers information tailored to different family members (Dads, grandparents, siblings) and there is a section for professionals with links to material on a variety of related topics, for example, “The Death of Twin Babies, Some Comments for Counselors”. This web site is full of information, resources and a bibliography. It also includes links to pamphlets.

Peek-a-boo ICU
http://www.peekabooicu.net/
This site was created by a registered nurse to provide support to parents as they face the emotional journey of the NICU. The information is intended to be easy to understand and to empower parents with knowledge. The website also offers support and encouragement by relaying stories told from a nurse’s perspective. A section called “NICU 10” covers topics such as the importance of sleep and fighting infections. Short articles on NICU related topics appear under a section called “Crib Notes” and Preemie Power”. Some articles address the development of a premature baby, for example, a description of babies born 24 weeks
Internet Resources, continued

through 36 weeks appears in the article “Your Growing Preemie Week by Week” which appears in the Preemie Power section.

Angel Twin Moms with Survivors
http://health.groups.yahoo.com/group/angeltwinmoms-survivors/

This is a Yahoo Group focusing on infant loss support for moms who have lost a twin or higher multiples, and have a survivor(s). The group description focuses on the common bond between moms who have experienced a miscarriage, stillbirth, neonatal loss, early infant loss or Sudden Infant Death Syndrome (SIDS).

Insurance

SSI (Supplemental Security Income)
(800) 772-1213
www.ssa.gov/

Social Security provides SSI disability benefits (including Medicaid) to certain infants born with a low birth weight whether or not they are premature. A child weighing less than 1200 grams (about 2 pounds, 10 ounces) at birth can qualify for SSI based on low birth weight. A child weighing between 1200 and 2000 grams (about 4 pounds, 6 ounces) at birth and considered small for his or her gestational age also may qualify.

http://ssa-custhelp.ssa.gov/app/answers/detail/a_id/368

Family and Medical Leave Act (FMLA)

The federal Family and Medical Leave Act (FMLA)provides certain employees with up to 12 weeks of unpaid, job-protected leave per year. It also requires that their group health benefits be maintained during the leave. FMLA is designed to help employees balance their work and family responsibilities by allowing them to take reasonable unpaid leave for certain family and medical reasons. It also seeks to accommodate the legitimate interests of employers and promote equal employment opportunity for men and women.

FMLA applies to all public agencies, all public and private elementary and secondary schools, and companies with 50 or more employees. These employers must provide an eligible employee with up to 12 weeks of unpaid leave each year for any of the following reasons for the birth and care of the newborn child.
of an employee; for placement with the employee of a child for adoption or foster care; to care for an immediate family member (spouse, child, or parent) with a serious health condition; or to take medical leave when the employee is unable to work because of a serious health condition.

The Texas Health Insurance Pool
(888) 398-3927  Risk pool for those persons who are uninsurable.
www.txhealthpool.org

CHIP- Children’s Health Insurance Program
(800) 647-6558  A national program designed for families who earn too much money to qualify for Medicaid, yet cannot afford to buy private insurance.
http://www.chipmedicaid.com/

CHIP – Perinatal Children’s Health Insurance Program
(877) 543-7669  The Children’s Health Insurance Program (CHIP) perinatal coverage provides perinatal care for the unborn children of low-income women who do not qualify for Medicaid. CHIP perinatal coverage starts before the child is born and lasts 12 months from the date the unborn child is enrolled.
http://www.chipmedicaid.org/en/CHIP-Perinatal

HIPP – Health Insurance Premium Payment Reimbursement Program
(800) 440-0493  This is a Medicaid program that pays for the cost of premiums, coinsurance, deductibles, and other cost sharing. The program reimburses the policy holder due to private health insurance payroll deductions for Medicaid eligible persons when it is determined to be cost effective.
www.gethipptexas.com

Medicaid
(800) 252-8263  Low-income families may qualify for this program by income or in extreme situations when medical expenses exceed income. The website includes information on other Medicaid programs like Kidney Health Care, Medical Transportation and others
www.hhsc.state.tx.us/medicaid/contacts.html

Medicaid-Texas Health Steps
(877) 847-8377  This program makes sure that complete health services are available to children, teens and young adults up to the age of 21, who are enrolled in Medicaid. This includes medical and dental check-ups, eye and hearing
screenings, lab tests and shots, eye glasses and hearing aids, prescriptions, and case management for children with special health care needs.

http://www.dshs.state.tx.us/thsteps/

**CSHCN - Children with Special Health Care Needs**  
(800) 252-8023  
The Children with Special Health Care Needs (CSHCN) is made up of several programs that provides services to children with extraordinary medical needs, disabilities, and chronic health conditions. The CSHCN health care benefits program pays for medical care, family support services, and related services not covered by Medicaid, CHIP, private insurance, or other “third party payor.”

www.dshs.state.tx.us/cshcn

**Pre-Existing Condition Insurance Plan (PCIP)**  
(866) 717-5826  
Federal Program – Providing health coverage for eligible children and adults with pre-existing conditions.

www.pcip.gov

**Medicaid Buy-In for Children**  
1-877-541-7905  
Medicaid Buy-In for Children can help pay medical bills for children with disabilities. This program helps families who need health insurance, but make too much money to get traditional Medicaid. Families “buy in” to Medicaid by making a monthly payment (premium).

http://www.hhsc.state.tx.us/Help/HealthCare/Children/MBIC.html

**Shriners Hospitals for Children**  
800-237-5055  
Children up to the age of 18 with orthopedic conditions, burns, spinal cord injuries and cleft lip and palate are eligible for admission and receive all care in a family-centered environment at no charge regardless of financial need.

www.shrinershq.org/Hospitals

**Transportation**

**Medical Transportation Program** (through TX Dept. of Transportation)  
(877) 633-8747  
Provides eligible Medicaid clients, under 21 with non-emergency transportation services to Medicaid covered medical and dental care.

www.hhsc.state.tx.us/QuickAnswers/GetRide_FAQs.shtml
Other Services:

The Arc of Texas
(800) 252-9729
www.thearcoftexas.org

The Arc of Texas is affiliated with the Arc of the United States and has 48 chapters in Texas working to provide additional community supports and services to families with children or individuals with intellectual and developmental disabilities throughout the State.

Advocacy

Disability Rights Texas
(800)-252-9108

www.disabilityrightstx.org

A Federally funded agency (every state has one) that advocates for people with disabilities. They can only help people whose issues are one of their current priorities although their website has lots of useful information and they can send you information. Sometimes a call can get you an answer to a specific question. State office located in Austin, with branches around the state.
Medicaid Waiver Programs

These programs are based on child’s income (not the parents) in order for them to qualify for Medicaid and receive additional services that will allow a child to remain in the community as opposed to a nursing home or institution. The programs provide funding for a personal attendant, respite, therapies, adaptive aids, home and vehicle modifications, etc.

The below listed programs are all found on the following website:  
www.dads.state.tx.us

MDCP (Medically Dependent Children’s Program)

(877) 438-5658 This program provides a variety of services to support families caring for children who are medically dependent and to keep the children in their communities.

www.dads.state.tx.us/services/faqs-fact/mdcp.html

In-Home and Family Support Services

(877) 438-5658 This program provides direct grant benefits to adults and children with disabilities to purchase services to let them live in the community.

(Waiting list)

www.dads.state.tx.us/services/faqs-fact/ifs.html

CLASS (Community Living Assistance Support Services)

(877) 438-5658 This program provides home- and community-based services to people with related conditions as a cost-effective alternative to placement in an intermediate care facility. (A related condition is a disability, other than mental retardation, that originated before age 22 and that affects the ability to function in daily life.)

(Waiting list)

www.dads.state.tx.us/services/faqs-fact/class.html

Community Based Alternatives (CBA)

(800) 458-9858 This program provides home- and community-based services to people who are elderly and to adults with disabilities as a cost-effective alternative to living in a nursing home.

(Waiting list)

www.dads.state.tx.us/services/faqs-fact/cba.html

MRLA (Mental Retardation Local Authority) or
HCS (Home and Community Services)

(800) 458-9858 MHMR Medicaid waiver programs (Waiting list)

www.dads.state.tx.us/services/faqs-fact/hcs.html
Medicaid Waiver’s continued

Texas Home Living Program (TxHmL)

(800) 458-9858 Provides selected essential services and supports to people with intellectual and developmental disabilities who live in their family homes or their own homes.

www.dads.state.tx.us/services/faqs-fact/txhml.html

You may need to contact your local Texas Department of Aging and Disability Services to find out what specific Medicaid Waiver Programs are available in your area.

National Resources

NICHCY (National Dissemination Center for Children with Disabilities)

(800) 695-0285 Disability library and information on related services; produces state resource sheet.

http://nichcy.org

Exceptional Parent Magazine

(877) 372-7368 Monthly magazine for parents and professionals; National website includes resources for parent to parent programs; information and referral centers, disability library, services, products and much more.

www.eparent.com

Family Village A global community that integrates information, resources, disabilities

www.familyvillage.wisc.edu library and communication opportunities on the internet

NORD (National Organization for Rare Disorders)

(800) 999-6673 Information and referrals on rare disorders

www.rarediseases.org

MUMS (Mothers United for Moral Support)

(920) 336-5333 National parent to parent network which provides information and emotional support to parents whose child has a rare disorder.

(877) 336-5333
(toll free for parents only)

www.netnet.net/mums/
National Resources, continued

NIH (National Institute of Health)
(301) 496-4000
www.nih.gov
Stephen Groft at the office of rare diseases provides information on which hospitals and physicians are doing research or clinical trials on any disease.

NAMI (National Association for Mental Illness)
(800) 950-6264
www.nami.org
Provides information and training programs for caregivers of individuals with mental health issues or brain disorders.

National Fathers Network
www.fathersnetwork.org/
Provides training and emotional support for fathers of children with special health care needs and developmental disabilities.

Please visit our website Resource Directory for other resources that may be available in your area. We appreciate your notifying us of any changes that may need to be made to this list or the website. www.txp2p.org

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