



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
(877) 541-7905
(877) 833-4211 (TTY)
<https://www.211texas.org>

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 x7726
<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,



Services continued

breastfeeding information and help accessing health care to low-income women, infants, and children.

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

817-810-9984

<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.

Texas Health & Human Services (HHS)

ECI (Early Childhood Intervention)

(877) 787-8999

<https://hhs.texas.gov/services/disability/early-childhood-intervention-services>

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.



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Services continued

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.

Texas Health & Human Services (HHS)

The Blind Children’s Vocational and Discovery Program

<https://hhs.texas.gov/blind-childrens-vocational-discovery-development-program>

As of September 1, 2016, programs and services previously administered or delivered by the former Texas Department of Assistive and Rehabilitative Services (DARS) have been transferred by the Texas Legislature to the [Texas Workforce Commission](#) or the [Texas Health and Human Services Commission](#).

Texas Health & Human Services (HHS)

Deaf and Hard of Hearing Services

<https://hhs.texas.gov/services/disability/deaf-hard-hearing>

As of September 1, 2016, programs and services previously administered or delivered by the former Texas Department of Assistive and Rehabilitative Services (DARS) have been transferred by the Texas Legislature to the [Texas Workforce Commission](#) or the [Texas Health and Human Services Commission](#).

Department of Aging and Disability Services (DADS)

(Moved to Health & Human Services)

(855) 937-2372 Long Term Care Services

<https://hhs.texas.gov/services/disability/consumer-directed-services>

Information on long term care services and consumer directed services

Texas Department of State Health Services, Information on Zika Virus

(888) 963-7111

www.texaszika.org

www.cdc.gov/zika/parents/index.html

The Department of State Health Services (DSHS) has information on the website about the Zika virus and how it affects pregnant women. Steps to avoid mosquito bites and an infection are also included. Fact sheets and cards are available for distribution. DSHS works closely with the Centers for Disease Control and Prevention (CDC) to educate the public. The CDC website also has helpful information on the Zika virus for parents.



Services continued

InfantSee

(888) 396-3937

www.infantsee.org

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 InfantSee website includes information for parents about vision milestones and activities to develop vision. It also includes eye health terms and a locator to find participating providers.

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.

Multiples of America (formerly known as The National Organization of Mothers of Twins Clubs, Inc)

www.multiplesofamerica.org

Multiples of America 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 web site 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>



Internet Resources, continued

Inspire-Preemie Support Community

<https://www.inspire.com/groups/preemie/>

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.

Preemies Today

www.preemiestoday.org

info@preemiestoday.org

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).

Preemie Prints

(979) 635-0825 amber@preemieprints.org

(512) 786-3232 sherri@preemieprints.org

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

(847) 434-0000

<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.



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Internet Resources, continued

Zero to Three

(202) 638-1144 general info

(800) 899-4301 book store

<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.

Parent Companion

www.parentcompanion.org

An online guide for parents and caregivers of children suspected or diagnosed with a delay, disability, or medical condition. This website has a section on being in the NICU. Videos of families talking about their experiences are featured.

National Perinatal Association

www.nationalperinatal.org

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.

climb@climb-support.org Jean Kollantai

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.



Internet Resources, continued

Peek-a-boo ICU

<http://www.peakabooicu.com>

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

Journey of Hearts

www.journeyofhearts.org

griefdoc@journeyofhearts.org

The site was created to serve as an online healing place with resources and support to help those through the grief process following a loss, crisis, or significant life change.

The Compassionate Friends

www.compassionatefriends.org

(877) 969-0010

The Compassionate Friends site provides personal comfort, hope, and support to every family experiencing the death of a family member.

Navigate Life Texas

www.navigatelifetexas.org

Statewide website created for parents of children with disabilities or special health care needs. Designed to offer support, inspiration, resources, and links to services available, there is a helpful library of video stories and discussions on a variety of topics.



Internet Resources, continued

Graham's Foundation

<http://grahamsfoundation.org>

(888) 466-2948

This foundation was created to offer care packages that offer practical and emotional support. Three care packages, the NICU Package, the Transition Home Care Package, and the Remembrance Care Package are available by request through the website. A small donation to cover shipping and handling is requested. The website also includes an extensive list of parent resources including recommended books, blogs, websites plus Facebook and Twitter links.

Mommies of Miracles

<http://mommiesofmiracles.com>

This is a virtual support group for mothers of children who have medical complexities, life-limiting conditions, or developmental disabilities. This website offers support, matching families and tools. A resource directory covers everything from Accessible Technology, Adaptive Equipment to Churches and Ministries that are supportive of people living with disabilities. Care Pages and Medical Quick Reference tabs lead to pages that provide documents to help with organizing and documenting medical information.

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)

<http://www.dol.gov/dol/topic/benefits-leave/fmla.htm>

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.**



Insurance continued

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.

CHIP- Children's Health Insurance Program

<http://www.chipmedicaid.com/>

2-1-1, option 2

A national program designed for families who earn too much money to qualify for Medicaid, yet cannot afford to buy private insurance.

CHIP – Perinatal Children's Health Insurance Program

<http://www.chipmedicaid.org/en/CHIP-Perinatal>

2-1-1, option 2

The Children's Health Insurance Program (CHIP) perinatal coverage provides prenatal 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.

HIPP –Health Insurance Premium Payment Reimbursement Program

www.gethipptexas.com

(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.

Medicaid

<https://hhs.texas.gov/services/health/medicaid-chip/programs/medicaid-buy-adults>

(800) 252-8263

BUY IN: (877) 541-7905

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



Insurance, continued

Medicaid-Texas Health Steps

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

(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.

CSHCN - Children with Special Health Care Needs

www.dshs.state.tx.us/cshcn

(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.”

Medicaid Buy-In for Children

<https://texasmedicaidwaivers.com/medicaid/medicaid-buy-in-programs/medicaid-buy-in-for-children/>

(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).

Shriners Hospitals for Children

www.shrinershospitalsforchildren.org

(409) 770-6600

(713) 797-1616

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.

Texas Scottish Rite Hospital

<https://scottishritehospital.org>

(214) 559-5000

(800) 421-1121

TSRHC treats children with orthopedic conditions such as scoliosis, clubfoot, hand disorders, hip disorders, and limb length differences, as well as sports injuries, and certain related neurological disorders and learning disorders, such as dyslexia. There is a financial assistance program.



Other Services:

The Arc of Texas

www.thearcoftexas.org

(800) 252-9729

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

www.disabilityrightstx.org

(800)-252-9108

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 websites:

<https://hhs.texas.gov/services/disability>

<https://hhs.texas.gov/services/disability/consumer-directed-services>

<https://www.navigatelifetexas.org/en/insurance-financial-help/texas-medicaid-waiver-programs-for-children-with-disabilities>

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.

In-Home and Family Support Services

(855) 937-2372

This program provides direct grant benefits to adults and children with disabilities to purchase services to let them live in the community.
(Waiting list)



Medicaid Waiver Programs, continued

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)

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

(800) 458-9858

MHMR Medicaid waiver programs (Waiting list)

Texas Home Living Program (TxHmL)

(Contact Local Authority) Provides selected essential services and supports to people with intellectual and developmental disabilities who live in their family homes or their own homes.

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

Exceptional Parent Magazine

(877) 372-7368 x234

www.eparent.com

Monthly magazine for parents and professionals; National website includes resources for parent to parent programs; information and referral

NORD (National Organization for Rare Disorders)

www.rarediseases.org

Information and referrals on rare disorders.

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.



National Resources Continued

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

(425) 653-4286

www.fathersnetwork.org/

Provides training and emotional support for fathers of children with special health care needs and developmental disabilities.

Foundation for Children with Microcephaly

(877) 476-5503

www.childrenwithmicro.org

An organization and website to support and inform parents and families of children who have been diagnosed with Microcephaly, Lissencephaly, Polymicrogyria, and other closely related disorders.

Syndrome Without A Name (SWAN)

(888) 880-SWAN

info@swanusa.org

www.swanusa.org

A resource for families with a child with an undiagnosed genetic condition or disorder. Includes information and videos. A network of families can be joined through their website.

Unique- The Rare Chromosome Disorder Support Group

<http://www.rarechromo.org>

info@rarechromo.org

International group with a mission to inform, support, and connect families impacted by a rare chromosome disorder.

Center for Parent Information and Resources

www.parentcenterhub.org

Find resources of interest on a variety of disability and education topics. Resources are also available in Spanish.



National Resources (continued)

American Brain Foundation

(866) 770-7570

www.americanbrainfoundation.org

Find resources on how to prepare for a visit to a neurologist, tips, and information on diseases of the brain/central nervous system. Books, materials, and videos are available.

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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