



Texas Parent to Parent NICU State Resources

Name	Phone Number	Description	Web Link
Texas Parent to Parent	(512) 458-8600 (866) 896-6001	Provides parent to parent matches, emotional support and information for parents of babies who spent time in a Neonatal Intensive Care Unit. A statewide non-profit developed for parents by parents. Supports parents of children with disabilities, chronic illness, and other special healthcare needs.	www.txp2p.org
Parent Companion		An on-line 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.	http://www.parentcompanion.org/
Human Milk Banking Association of North America		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, and the Mother's Milk Bank of North Texas, both are HMBA affiliates and their websites are helpful in locating milk drop off locations around the state.	https://www.hmbana.org/ http://www.milkbank.org/ http://www.texasmilkbank.org/
2-1-1 Texas	(877) 541-7905	2-1-1 Texas provides information on and access to Medicaid, Supplemental Nutrition and Food Assistance Program (SNAP), Temporary Assistance for Needy Families (TANF), Children's Health Insurance, 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.	https://www.211texas.org



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<p>Texas Health and Human Services Commission (HHSC) ECI (Early Childhood Intervention)</p>	<p>(877)-787-8999</p>	<p>Services for children, birth to 3-years-old, who have a developmental delay or disability. (Including babies born with a brain abnormality, like microcephaly.) 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 the development of an Individualized Development Plan (IFSP). 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 and services.</p>	<p>https://hhs.texas.gov/services/disability/early-childhood-intervention-services</p>
<p>Texas Department of State Health Services, Information on the Zika Virus</p>	<p>888-963-7111</p>	<p>The Department of State Health Services (DSHS) has information about the Zika Virus and how it affects pregnant women on their website. 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.</p>	<p>http://www.texaszika.org/ https://www.cdc.gov/zika/parents/index.html</p>
<p>HHSC, The Blind Children's Vocational and Discovery Program</p>	<p>(877)-787-8999</p>	<p>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.</p>	<p>https://hhs.texas.gov/services/disability/blind-and-visually-impaired/blind-childrens-vocational-discovery-and-development-program</p>



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HHSC, Deaf and Hard of Hearing Specialist Program	(877)-787-8999	<p>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.</p>	http://legacy.hhsc.state.tx.us/dhhs/specialistpgm.shtml
HHSC, Department of Aging and Disability Services & The Department of State Health Services-Medicaid Waiver Programs	800-458-9858	<p>Programs to provide long term care and supports for children and adults with intellectual and physical disabilities. There are very long waiting lists. Put your child's name on the lists for all the waiver programs as soon as you suspect or know your child has a disability.</p> <p>The programs provide funding for a personal attendant, respite, therapies, adaptive aids, home and vehicle modifications, etc.</p>	https://hhs.texas.gov/services/disability https://www.navigatelifetexas.org/en/insurance-financial-help/texas-medicaid-waiver-programs-for-children-with-disabilities
Texas Early Hearing Detection and Intervention (TEHDI)	(800) 252-8023	<p>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.</p>	http://txehdi.org/families/
Texas Department of State Health Services, Women, Infants and Children Program (WIC)	(800) 942-3678	<p>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.</p>	http://texaswic.dshs.state.tx.us/wiclessons/english/splash/



Texas Parent to Parent NICU Resources Insurance

Name	Phone Number	Description	Web Link
SSI (Supplemental Security Income)	(800) 772-1213	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 who is diagnosed as “failure to thrive” may also qualify.	www.ssa.gov/ https://www.ssa.gov/pubs/EN-05-10026.pdf https://www.ssa.gov/disability/professionals/bluebook/100.00-GrowthImpairment-Childhood.htm
Medicaid	(800) 252-8263	Low-income families may qualify for this program by income or in extreme situations when medical expenses exceed income	https://hhs.texas.gov/services/health/medicaid-and-chip
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/



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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).	https://hhs.texas.gov/services/health/medicaid-and-chip/programs/medicaid-buy-children
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 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.	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



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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
Shriners Hospitals for Children	813-281-0300	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.	http://www.shrinershospitalsforchildren.org/
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	http://www.dol.gov/dol/topic/benefits-leave/fmla.htm



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Family and Medical Leave Act (FMLA)		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	http://www.dol.gov/dol/topic/benefits-leave/fmla.htm
InfantSee	1-888-396-3937	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 locator to find optometrist providers for the InfantSee program.	http://www.infantsee.org/



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Affordable Care Act	800-318-2596	Federal law designed to expand insurance coverage and reduce the costs of healthcare. Federal subsidies are available depending on your income.	https://www.healthcare.gov/
Texas Scottish Rite Hospital	214-559-5000 or 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.	http://www.tsrhc.org/



Texas Parent to Parent NICU Resources Information & Support

Name	Description	Web Link
March of Dimes-NICU	This website features information for parents of babies in the NICU. It 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. There is also includes a mechanism for submitting questions.	http://www.marchofdimes.org/complications/the-nicu.aspx
American Academy of Pediatrics/ About HealthyChildren.org	HealthyChildren.org is a parenting website backed by the American Academy of Pediatrics. It provides general information related to child health, child development and guidance on parenting issues. Covered topics include ages and stages information (including a section on premies, the health issues of premature babies, life in the NICU, going home and caring for a premature baby). The Ages and Stages information covers prenatal to young adult. 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.	http://www.healthychildren.org/english/ages-stages/Pages/default.aspx
The Maison Alexander Support Group Inc.	The Maison Alexander Support Group Inc. is a Texas 501(c) 3 non-profit organization that assists families during their time in the NICU. They have a "NICU Buddy Program" a "Pump, Eat & Sleep" brochure, and they can provide gas cards and food cards, premature clothing, and infant items if there is need. They also have "Mommy Love" Program geared towards expecting mothers.	http://www.masgnicu.org/
Preemie Prints	Preemie Prints is a Texas 501(c) 3 nonprofit organization dedicated to sharing hope with families experiencing the	www.preemieprints.org



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	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 online support, meetings, and events, to connect past and present NICU families.	
Graham's Foundation	This organization provides support to families of premature babies. They have a care package program and trained mentors available 24/7. Their website has resources, information about a preemie app and information sheets.	http://grahamsfoundation.org/
Preemies Today	Preemies Today is a national support network and a non-profit organization founded by parents of preemies. Resources include blogs, articles and stories to help new preemie parents. Topics covered include breast pumping and feeding, coming home, early intervention, baby and toddler activities, emotional health, Medicaid and financial assistance and pregnancy after a preemie. They also feature an on-line forum, where participants can ask questions of other preemie parents.	http://www.preemiestoday.com
PreemieCare	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.	http://www.preemiecure.org/index.htm
Peek-a-boo ICU	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	http://www.peakabooicu.net/



Texas Parent to Parent NICU Resources Information & Support

	<p>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 “Premie Power”. Some articles address the development of a premature baby, for example, a description of babies born 24 weeks.</p>	
<p>National Perinatal Association</p>	<p>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.</p>	<p>http://www.nationalperinatal.org/index.php</p>
<p>Zero to Three</p>	<p>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.</p>	<p>http://www.zerotothree.org/</p>
<p>La Leche League</p>	<p>Their Mission is to help mothers worldwide to breastfeed through mother-to-mother support, encouragement,</p>	<p>http://www.llli.org/ (800) 525-3243 (Office)</p>



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	<p>information, and education, and to promote a better understanding of breastfeeding as an important element in the healthy development of the baby and mother.</p> <p>Their website includes links to helpful resources, includes FAQ (frequently asked questions) information and articles on breastfeeding a preemie, plus downloadable podcasts on a variety of topics.</p>	(877) 452-5324 (Helpline)
Multiples of America	<p>Multiples of America (also known as 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.</p>	http://www.nomotc.org/
Inspire-Preemie Support Community	<p>Inspire connects patients, families, friends, caregivers, and health professionals for health and wellness support. There are several Preemie Support Communities that foster online discussion and support networks.</p>	https://www.inspire.com/conditions/premature-babies/



Texas Parent to Parent NICU Resources

Other Helpful Information

Name	Phone Number	Description	Web Link
Grief & Loss			
CLIMB, The Center for Loss in Multiple Birth, Inc.		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.	http://www.climb-support.org
The National Association of Perinatal Social Workers		This organization lists resources to support families with a sick infant or who have lost a baby before, during or after birth.	https://napsw.memberclicks.net/resources
Journey of Hearts		This 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 a significant life change.	http://www.journeyofhearts.org/index.html
The Compassionate Friends		The Compassionate Friends provides personal comfort, hope, and support to every family experiencing the death of a family member.	https://www.compassionatefriends.org/find-support/



Texas Parent to Parent NICU Resources Other Helpful Information

Transportation			
Medical Transportation Program	(877) 633-8747	Provides eligible Medicaid clients, under 21 with non-emergency transportation services to Medicaid covered medical and dental care.	https://hhs.texas.gov/services/health/medicaid-and-chip/programs/texas-medicaid-and-chip-medical-transportation-program
Disability			
Navigate Life Texas		Statewide website created for parents of children with disabilities or special health care needs. It is 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.	https://www.navigatelifetexas.org
The Arc of Texas	(800) 252-9729	The Arc of Texas is affiliated with the Arc of the United States and has 35 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.	www.thearcoftexas.org
Disability Rights Texas	(800)-252-9108	A federally funded agency (every state has one) that advocates for people with disabilities. They have a website with useful information and resources.	https://www.disabilityrightstx.org/
National Fathers Network		Provides training and emotional support for fathers of children with special health care needs and developmental disabilities.	www.fathersnetwork.org/



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Other Helpful Information

Foundation for Children with Microcephaly	877-476-5503	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 neurological disorders.	http://www.childrenwithmicro.org/index.html
NORD (National Organization for Rare Disorders)	(800) 999-6673	Information and referrals on rare disorders	www.rarediseases.org
Syndrome Without a Name (SWAN)	(269)-692-2090	A resource for families with a child with an undiagnosed genetic conditions or disorder. Includes information and videos. You can join a network of families through their website. They are based in the United Kingdom.	https://www.swanusa.org
Unique-The Rare Chromosome Disorder Support Group		This is an international group with a mission to inform, support and connect families impacted by a rare chromosome disorder.	http://www.rarechromo.org/html/home.asp
Center for Parent Information and Resources		Find resources of interest on a variety of disability and education topics. Resources are available in Spanish.	http://www.parentcenterhub.org/
American Brain Foundation		Find resources on how to prepare for a visit to a neurologist and tips and information (books, materials and videos) on diseases of the brain and central nervous system.	http://americanbrainfoundation.org/