



# Texas Parent to Parent NICU Información y Recursos de la Nación

## Texas Parent to Parent

(512) 458-8600

(866) 896-6001

[www.txp2p.org](http://www.txp2p.org)

Organización estatal sin fines de lucro creada para proveer servicios de padre a padre, apoyo emocional e información para padres cuyos bebés pasaron tiempo en la Unidad de Cuidado Intensivo Neonatal.

### **Misión:**

Texas Parent to Parent apoya a niños con discapacidad, enfermedades crónicas y otras necesidades especiales de salud apoderando a sus padres para convertirlos en sus intercesores a través de apoyo entre padres, encontrar recursos en la comunidad que pueda necesitar y conciencia pública.

## *Servicios*

### 2-1-1 Texas

2-1-1

(877) 541-7905

(877) 833-4211 (TTY)

2-1-1 Texas provee información y el acceso a Medicaid, Cupones para Alimentos, Asistencia Temporal para Familias Necesitadas (TANF), Salud infantil, Seguros, cuidado de ancianos y otros servicios. Cuando marcan el <https://www.211texas.org> 2-1-1, accedes a los centros de información de área en su región. 2-1-1 es una colaboración con la Comisión de Salud y Servicios Humanos y de información de área Centros en todo el estado. El objetivo es lograr en una llamada, conectar con recursos integrales y comunitarios, la información es confidencial.

## Texas Early Hearing Detection and Intervention (TEHDI)/Detección e Intervención Temprana de la Audición

(800) 252-8023

<http://www.dshs.state.tx.us/tehdi/Audiology-Services-Home.aspx>

El programa (TEHDI, por sus siglas en inglés) está diseñado para detectar posible pérdida de audición en los recién nacidos, realizar pruebas para definir el grado y tipo de pérdida de audición, encontrar el equipo de ayuda auditiva apropiada, e inscribirlos en los servicios de intervención antes de los seis meses de edad.

## Texas Department of State Health Services, Women, Infants and Children Program (WIC) Departamento de Servicios de Salud para mujeres, infantes y niños de Texas

(800) 942-3678

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

Es un programa de nutrición que ayuda a mujeres embarazadas, madres y niños pequeños a comer bien y mantenerse saludable. WIC ofrece educación nutricional y asesoramiento, alimentos nutritivos, información sobre lactancia y ayudar a acceder a cuidados de salud para mujeres, bebés y niños de bajos recursos.



## **Continuación de Servicios**

El sitio de internet leche materna, cada onza cuenta de WIC tiene un enlace para identificar recursos de la comunidad para apoyar la lactancia materna, incluyendo clínicas de WIC y bancos de leche. En el enlace "Cada onza cuenta" usted puede crear su propia tarjeta de natalicio; también hay un enlace a "Cántame" - Un Álbum Canciones de cuna que incluye canciones de músicos de Texas para las madres y los bebés e incluye un archivo descargable de todas las canciones. <http://www.breastmilkcounts.com/resources.html>

## **Texas WIC Breast Pump Program/ Programa de Extracción de leche**

**(800) 942-3678**

[www.texaswic.org](http://www.texaswic.org)

Todas las mamás de WIC con un infante prematuro o que están separados de su bebé debido a razones médicas son elegibles para recibir (prestada) una bomba de grado hospitalario. Las mujeres que no están inscritos en el programa WIC podrían calificar con base en los ingresos del hogar. Póngase en contacto con una oficina local de WIC para más información.

## **Human Milk Banking Association of North America/ Asociación de Banco de leche**

<https://www.hmbana.org/>

Este sitio web proporciona información sobre la ubicación de los bancos de leche afiliados, su historia, respuestas a preguntas frecuentes (FAQ), cómo se procesa la leche de donantes y cómo donar leche. También hay enlaces para ordenar publicaciones y otros recursos. El Banco de Leche de la Madre Austin, <http://www.milkbank.org/> y el Banco de leche de la madre de North Texas, <http://www.texasmilkbank.org/> ambas están filiadas a HMBA y sus sitios web son útiles en la localización de centros para dejar la leche en todo el estado.

## **Department of Assistive and Rehabilitative Services (DARS)/Departamento de Servicios de Asistencia y Rehabilitación**

### **ECI (Early Childhood Intervention)/ Intervención Infantil Temprana**

**(800) 628-5115**

**(866) 581-9328 TTY**

[www.dars.state.tx.us/ecis/](http://www.dars.state.tx.us/ecis/)

Servicios para niños, nacimiento hasta los 3 años de edad, que tienen un retraso o discapacidad del desarrollo. Los servicios se proporcionan en el hogar y la comunidad. ECI utiliza un enfoque de equipo centrado en la familia para desarrollar un plan para la familia para ayudar al niño a crecer y aprender. Los miembros del equipo provienen de una variedad de profesiones incluyendo especialistas de intervención temprana, enfermeras, dietistas, terapeutas y trabajadores sociales. **No hay ningún costo para la familia durante una intervención.** Los servicios se ofrecen en una escala variable, pero ninguna familia se les negará servicios debido a la imposibilidad de pagar. ECI produce una gama de materiales útiles para las familias, incluyendo una guía de recursos que describen los programas, servicios y recursos para las familias.



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## **Continuación de Servicios**

### **Division for Blind Services (DARS)/ División de servicios para ciegos**

**Formerly Texas Commission for the Blind/ Antes Comisión de Texas para ciegos**

**(800) 628-5115**

**(866) 581-9328 TTY**

[www.dars.state.tx.us/dbs/](http://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](http://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](http://www.dads.state.tx.us)

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



## **Apoyo en internet e información sobre bebés prematuros**

### **La Leche League/ La liga de la leche**

<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 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/>

### **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**

<http://preemievoices.com/Default.aspx>

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



## **Continuación Recursos en Internet**

### **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).

### **Premie Care**

<http://www.premiecare.org/index.htm>

PremieCare 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. PremieCare has a special focus on RSV awareness and prevention. Issues such as breastfeeding preemies, parenting in the NICU, early intervention are also addressed by PremieCare, as are networking opportunities for preemie support groups.

### **Premie Prints**

[www.premieprints.org](http://www.premieprints.org)

Premie 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. Premie 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.

### **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.



## **Continuación Recursos en Internet**

### **National Perinatal Association**

<http://www.nationalperinatal.org/index.php> Llame gratis: (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.peakabooicu.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 "Premie 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 Premie Week by Week"* which appears in the *Premie 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).



## **Recursos en Internet, continuación**

### **Graham's Foundation**

<http://grahamsfoundation.org>

1-888-466-2948

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.

## **Seguros**

### **SSI (Supplemental Security Income)**

(800) 772-1213

[www.ssa.gov/](http://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](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.** 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.





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## **Seguros, continuación**

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](http://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 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](http://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](http://www.hhsc.state.tx.us/medicaid/contacts.html)





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## **Seguros, continuación**

### **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](http://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](http://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](http://www.shrinershq.org/Hospitals)



## **Transportación**

### **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](http://www.hhsc.state.tx.us/QuickAnswers/GetRide_FAQs.shtml)

## **Otros Servicios:**

### **The Arc of Texas**

**(800) 252-9729**

[www.thearcoftexas.org](http://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.

## **Abogacia:**

### **Disability Rights Texas**

**(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.

[www.disabilityrightstx.org](http://www.disabilityrightstx.org)

## **Programa Excensión de medicaid**

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](http://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](http://www.dads.state.tx.us/services/faqs-fact/mdcp.html)



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## **Medicaid Waiver Programs, continued**

### **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](http://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](http://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](http://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](http://www.dads.state.tx.us/services/faqs-fact/hcs.html)

### **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/txhtml.html](http://www.dads.state.tx.us/services/faqs-fact/txhtml.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.**



## **Recursos Nacionales**

### **NICHCY (National Dissemination Center for Children with Disabilities)**

(800) 695-0285

<http://nichcy.org>

Disability library and information on related services; produces state resource sheet.

### **Exceptional Parent Magazine**

(877) 372-7368

[www.eparent.com](http://www.eparent.com)

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.

### **Family Village**

[www.familyvillage.wisc.edu](http://www.familyvillage.wisc.edu)

A global community that integrates information, resources, disabilities library and communication opportunities on the internet

### **NORD (National Organization for Rare Disorders)**

(800) 999-6673

[www.rarediseases.org](http://www.rarediseases.org)

Information and referrals on rare disorders

### **MUMS (Mothers United for Moral Support)**

(920) 336-5333

(877) 336-5333

(toll free for parents only)

[www.netnet.net/mums/](http://www.netnet.net/mums/)

National parent to parent network which provides information and emotional support to parents whose child has a rare disorder.

### **NIH (National Institute of Health)**

(301) 496-4000

[www.nih.gov](http://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](http://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/](http://www.fathersnetwork.org/)

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

**Por favor visite nuestro Directorio de Recursos en la web para otros recursos disponibles en su área. Apreciamos que nos notifique si surgio algún cambio para actualizar nuestra lista. [www.txp2p.org](http://www.txp2p.org)**