

Spina Bifida in Texas

Spina Bifida, the most common, permanently disabling birth defect that is also compatible with life in the United States, affects approximately 1,500 births each year. Spina Bifida is a serious and life-long condition which occurs when the spinal cord fails to close properly during the early stages of pregnancy. Approximately 10% of babies born with Spina Bifida do not live into adulthood.

- In Texas, 3.58 babies are born with Spina Bifida per 10,000 births (data collection period: 2010).
- Recent research has estimated that the number of Americans living with all forms of Spina Bifida may be as high as 166,000. Based on this national estimate and the birth rate of Spina Bifida, approximately 8,709 people with Spina Bifida live in Texas.
- In Texas, there are an estimated 7.6 million women of childbearing age. All are atrisk of a Spina Bifida pregnancy. If women of childbearing age were to consume 400 micrograms (mcg) of the B-vitamin folic acid every day **before pregnancy**, the risk of Spina Bifida and other serious birth defects could be reduced by up to 70%.
- Approximately 6,967 of individuals with THE most serious form of Spina Bifida, myelomeningocele (MMC), suffer from hydrocephalus, a dangerous fluid build-up around the brain, which necessitates surgery to implant a shunt in the brain. Unfortunately, shunts require frequent revisions, and 5,574 of these devices will fail within 10 years.
- 4,355 of the people living with Spina Bifida are adults, and 3,484 of them have MMC. Very little is known about aging with Spina Bifida. Very few physicians are willing to treat people with Spina Bifida or have the knowledge of treatments and interventions associated with its management.

Cost Related to the Care of People with Spina Bifida in Texas

- The estimated cost of lifetime care related to Spina Bifida for the 1,100 of the people living with Spina Bifida in Texas can exceed \$1,000,000 or \$8,709,000,000. Among adults with MMC, only half live independently as adults, accruing substantial costs for the lifetime care.
- Out-of-pocket costs for direct medical care for children born with MMC are 13 times more than children born without MMC. These additional costs continue into adulthood, when individuals with MMC pay 7 times more in medical cost than those without MMC.
- Family caregivers for Spina Bifida patients are 25% less likely to be employed and, when they are employed, work 25% fewer hours compared to those not providing Spina Bifida-related care.

Clinics:

Dell Children's Medical Center Marnie Paul Specialty Center (0 – transition, adult) Austin, TX 78723 512-324-0137 <u>https://www.dellchildrens.net/service</u> <u>s-and-programs/specialty-care-</u> <u>center/spina-bifida-program/</u>

Moody Clinic (0 – 22) 1901 East 22nd St Brownsville, TX 78521 956-542-8504 www.moodyclinic.org https://scottishritehospital.org/careand-treatment/othertreatment/developmental-disabilities

Texas Tech Orthopaedic Surgery and Rehabilitation (Orthopedic, all ages) 4801 Alberta Avenue El Paso, TX 79905 915-215-5480 http://www.elpaso.ttuhsc.edu/som/Or thopaedics/

Texas Scottish Rite Hospital for Children Spina Bifida Clinic (Ages served: Information n/a) 2222 Welborn Street Dallas, TX 75219-3993 Cook Children's Hospital (0 – 18) 801 7th Avenue 682-885-2500 Fort Worth, TX 76104 <u>https://cookchildrens.org/neurology/c</u> <u>onditions/Pages/Spina-Bifida.aspx</u>

Baylor College of Medicine Transition Medicine Clinic

(transition)

7200 Cambridge St. 8th Floor, Suite 8A Houston, TX 77030 (713) 798-6333 https://www.bcm.edu/healthcare/car e-centers/transition-medicine/

Shriners Hospital for Children Houston (0 – 18) 977 Main Street Houston, TX 77030 713-797-1616 https://www.shrinershospitalsforchild ren.org/houston Texas Children's Hospital Spina Bifida Clinic (0 – 18) 6701 Fannin St. Suite 1610.01 Houston, TX 77030 832-822-4308 https://www.texaschildrens.org/depa rtments/spina-bifida-program

Methodist Children's Hospital Pediatric Specialty Clinics (0 – 18) Methodist Plaza, 4499 Medical Drive, Sublevel One San Antonio, TX 78229 (800) 297-1021 <u>https://sahealth.com/service/methodi</u> <u>st-pediatric-specialty-clinics</u>