



# EPILEPSY FOUNDATION

Texas - Houston/Dallas-Fort Worth/West Texas

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**2401 Fountain View Drive, Suite 900 – Houston, Texas 77057**

## **History of Epilepsy Foundation Texas and Epilepsy 101**

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Thirty-three years ago, in 1983, the Epilepsy Foundation of Southeast Texas was founded by Donna Stahlhut, after her son was diagnosed with epilepsy. At that time, Mrs. Stahlhut faced a perpetual lack of support and information; therefore, taking a proactive stand, she installed a phone in her kitchen and established a network of information, resources, and support for families dealing with the multi-dimensional difficulties associated with epilepsy. Over the last 30 years of service, the Epilepsy Foundation has established many life changing programs and services in order to meet the varied needs of people with epilepsy and their loved ones.

In 2008, the Epilepsy Foundation of Southeast Texas became the Epilepsy Foundation Texas, after expanding their service area to the north Texas region, when the Epilepsy Foundation of Greater North Texas closed their doors due to financial issues. The Epilepsy Foundation Texas answered the need by setting up an office and offering programs and services to people with epilepsy in the Dallas-Fort Worth area. In January of 2011, the Epilepsy Foundation Texas combined their efforts with the High Plains Epilepsy Association, a 38 year-old respected organization in the west Texas region, to create an even stronger and more united force in the fight against epilepsy, serving 176 counties in the state of Texas; **but the mission remains the same: To lead the fight against seizures, find a cure, and overcome the challenges created by epilepsy.**

By providing valuable information, life changing programs and services and a concentrated effort to raise awareness, we can have a tremendous impact on individuals with epilepsy, their families and the community as a whole.

Epilepsy is a mysterious disorder rooted in the complexities of the brain. It is a neurological condition that is caused by sudden brief changes in the brain's electrical balance; when there are excess electrical discharges in the brain, a seizure occurs. Seizures can alter awareness, physical movements, consciousness or actions and generally last from a few seconds to a few minutes. Epilepsy is terrifying, can be deadly and carries a tremendous stigma. Epilepsy is the most common neurological disorder in children, and third in adults. Updated statistics show that 1 in 26 people in the United States will develop epilepsy at some point in their lifetime. Each year there are 200,000 new cases of epilepsy diagnosed with the vast majority of those being children. Epilepsy can be fatal with death occurring while experiencing a seizure due to injury, asphyxiation, or a condition known as sudden unexpected death due to epilepsy (SUDEP). In fact, epilepsy claims as many lives as breast cancer each year.

The leading non-medical problem confronting people with epilepsy is discrimination; in education, employment and social acceptance. Oftentimes, society's reaction to the disorder is as damaging as the seizure itself. The Epilepsy Foundation Texas provides several programs to directly assist individuals and families. Through advocacy and education, the Epilepsy Foundation Texas can increase understanding of epilepsy to the public as well as individuals with epilepsy, to help erase the stigma and myths that surround the disorder.

The Foundation's goals include providing experiences to enrich the lives of individuals and families living with epilepsy, delivering easy access to reliable information, resources and support services, and ensuring access to specialized medical care for those most in need.

The Epilepsy Foundation Texas - Houston/Dallas/Fort Worth/West Texas is supported by private donations, special fundraising events, and state and federal dollars. **Of every dollar donated, 94 cents goes directly to programs and services to meet the needs of people with epilepsy. We are thus one of the most efficient charities in the country.**

## **EFTX's Current Programs:**

**Specialty Medical Care:** The most critical need of people with epilepsy is expert medical management, because specialized care is fundamental to limiting seizure activity. The Epilepsy Foundation Texas operates eight specialty medical clinics for uninsured/underinsured adults with epilepsy in our coverage area. Each year we see approximately 1,200 patients in one of our eight clinic locations. Nursing and support staff is available daily, via phone or email, to help manage patient needs between doctor visits.

The Epilepsy Foundation receives some funding from the Texas Department of State Health Services to assist in providing vital clinic services, though the dollars do not cover all of the expenses associated with the program. It costs the Epilepsy Foundation approximately \$400,000 per year for patient care.

Through our clinics, a patient receives all necessary clinic visits, diagnostic testing and prescription drugs at little or no cost. These patients are often unemployed due to inadequate seizure control, are unable to get health care through their employer, cannot afford to pay for an independent policy, and/or do not qualify for Medicare. Without the clinics, it would be virtually impossible for these patients to receive the care and medications required to treat their chronic and complex medical condition.

With improved access to specialty medical care and medication, our patients are able to gain better seizure control, experience less depression, and become productive members of society. Each year epilepsy programs save the state millions of dollars by keeping persons out of expensive emergency rooms.

**Camps:** The Epilepsy Foundation's award winning camping program is the largest camp in the country for children and teens with epilepsy. At a cost of \$1,000 per camper, the Foundation strives to provide this life changing camp experience, at no cost to families dealing with this expensive medical condition. Since 1991, the Epilepsy Foundation has conducted a summer camp program. From a humble beginning of 40 campers with one week long summer camp, the Foundation is now serving nearly 300 children and teens each summer through three amazing summer camp programs.

The Foundation's three week-long summer camps are: Camp Spike 'n' Wave®, which is held at Camp For All in Burton, Texas, for children ages 8 to 14. This camp is medically staffed by a team out of Texas Children's Hospital to ensure that each child's special medical needs are being met. Kamp Kaleidoscope®, which is held at the YMCA Collin County Adventure Camp in Anna, Texas, is specially designed for teens with epilepsy ages 15-19. Children's Medical Center of Dallas is our partner to provide the amazing medical team to handle this very unique camp. Camp Neuron®, which is held at Texas Lions Camp in Kerrville, Texas, is also for children 8 to 14. Cook Children's Medical Center medically staffs our newest camp that has now been in place for 4 years. With more than 20 years of experience in serving children with epilepsy, EFTX understands the positive impact that such an experience and support network can have on the lives of children with disabilities.

The mission of the Foundation's camping program is threefold: 1) to provide a safe, enjoyable, residential camp experience for children and teens with a primary diagnosis of epilepsy; 2) to build self-esteem by promoting self-confidence, competency and social interaction; and 3) to foster independence in a safe environment away from home. During the week of camp, these exceptional children enjoy many activities that others often take for granted. Camp activities range from basketball and horseback riding to swimming and arts & crafts projects where campers show their creative side. Campers also participate in the R.O.P.E.S. challenge course where they soar to new heights as they tackle the zip line. Activities are created that help build confidence and self-esteem, improve communication skills, nurture the development of friendships and promote social interaction. Campers learn to focus on what they are able to do rather than what they are not able to do. For several children, this camp is the only place to find friends with the same disorder and friends who truly understand them.

Following each summer camp, evaluations are sent to campers and their families to discover the internal and external changes of each camper. Parents often note how independent their child becomes after camp and how they begin to take on responsibility for their medications. Additionally, many parents discover that their child is more open to talking about their epilepsy and has gained self-esteem.

**Health and Well Being:** In 2012 the Epilepsy Foundation Texas was awarded a grant from the Texas Council of Developmental Disabilities to establish Get FIT Texas, a fitness and healthy life-style program for individuals with developmental disabilities (DD) and epilepsy and their caregivers. Get FIT Texas, is a health promotion initiative that seeks to prevent disease and improve the health of those with developmental disabilities. Get FIT aims at instilling the fundamentals of fitness, nutrition and a healthy lifestyle to this population that is nearly 60% more obese than the general population.

Through Get FIT Texas, participants receive an individual plan of action, including “at home” activities and training by a certified personal trainer. Individual dietary plans are also provided to program participants. Our coaches work one-on-one with the participants and their families, typically in a gym type setting.

Making changes in lifestyle and fitness can have a huge impact on the health status of people with developmental disabilities and their care givers. Although in 2013-2014, nearly 90% of the Get FIT participants were reported as clinically overweight, obese or morbidly obese, there was a marked improvement after a 12-week Get FIT program. Each participant lost pounds, and saw an average BMI reduction of 2.5%. Also, 94% of the participants lost inches off their waist and/or hips. In addition, 92% of participants improved muscular strength, endurance and flexibility. Such results illustrate the success of the Get FIT program.

The Epilepsy Foundation Texas is proud to offer these programs and services at no cost to the individuals and families who come seeking assistance from the Foundation. We very much appreciate you letting us share more about our organization and where our most financial needs currently lie.