

NCCDPHP Success Story

Increasing Delivery and Coordination of Epilepsy Care and Self-Management Supports: The Epilepsy Foundation Central & South Texas

PUBLIC HEALTH CHALLENGE

Since its founding in 1993, the Epilepsy Foundation Central & South Texas (EFCST) has been a lifeline for people with epilepsy in and around San Antonio.

One of the largest and most diverse metropolitan areas of the United States, Central and South Texas spans 79 counties and close to 90,000 square miles. Although the population has nearly doubled since the early 1990s, the region's entrenched poverty has persisted, with high rates of homelessness, limited public transportation, and large numbers of people who are uninsured.^a

That's made the work of EFCST more important. In addition to educating the public about epilepsy and dispelling popular myths about the condition, EFCST offers high quality clinical services for patients unable to afford specialized care. The EFCST has also received funding from the Centers for Disease Control and Prevention (CDC) to successfully deliver English and Spanish-language telehealth self-management programs from the CDC Managing Epilepsy Well (MEW) Network.

Notably, the EFCST has successfully put into action

four different MEW Network programs aimed at addressing the spectrum of needs experienced by adults struggling with epilepsy. EFCST has been an important partner of the University of Arizona and University of Texas CDC Prevention Research Centers (PRC) in further developing the epilepsy programs and evaluating their effectiveness.

Since 1995, the EFCST is run by Chief Executive Officer Ms. Sindi Rosales. Ms. Rosales's passion to help San Antonians with epilepsy was fueled by her own challenges obtaining care and support for her daughter, Jessica, diagnosed with Rasmussen's Encephalitis in 1993. A rare form of epilepsy, Rasmussen's is characterized by frequent, debilitating seizures.

"This horrific experience with our daughter taught me how few resources are available," Rosales recalls. "So, I threw everything I could into helping this community." In 1995, when she learned that the one local organization there to support people with epilepsy would soon be shut down, Rosales pleaded with the board of directors to let her take over as executive director and do what she could to keep it running. Since then, Rosales and her staff have built the EFCST into the model organization it is today.



a. <https://www.census.gov/data/tables/time-series/dec/cph-series/cph-4/cph-t-2.html>
<https://www.census.gov/data/tables/time-series/demo/popest/2010s-total-metro-and-micro-statistical-areas.html>
https://www.census.gov/data-tools/demo/sahie/#/?s_statefips=48&s_agecat=0
<https://www.sanantonio.gov/Portals/0/Files/HumanServices/FaithBased/2019PovertyReport.pdf>
<https://endhomelessness.org/homelessness-in-america/homelessness-statistics/state-of-homelessness-report/texas/>



APPROACH

Of the dozens of Epilepsy Foundation local offices nationwide, EFCST has long stood out, and not only for its inspiring origin story. With funding from the Texas Health and Human Services Commission, EFCST provides medical services directly to people with epilepsy who lack access to specialized medical care.

Using this state funding, EFCST operates seizure clinics staffed by board-certified neurologists in six cities across its service area, each offering everything from electroencephalograms (EEG) and magnetic resonance imaging (MRI) to emergency medication assistance and social service case management. “Our clinic program really sets us apart,” said Rosales. “We’re currently providing care for about 1,000 patients, and we think that’s really helped position us to participate in research projects on better treatments and care, including programs that support epilepsy self-management.”

The latter is a key component of comprehensive care for people with epilepsy, said EFCST Assistant Director Kimberly Martin, LVN. “If you’re able to manage your epilepsy, you can go back to work, be independent, and have a better quality of life. So that’s been a focus of ours for many years, and when these programs came out, we knew they could benefit this community.”

They started with MINDSET, a tablet-based decision-support tool that asks patients about their recent behaviors (e.g., adherence to treatment), emotional state (e.g., hopelessness), lifestyle (e.g., sleep quality), and health-related goals. That

information can help clinicians identify high-risk patients in need of self-management support and begin a dialogue about problem areas and strategies for coping. In 2014, researchers at the CDC-funded University of Texas (Houston) PRC approached Rosales and Martin about studying MINDSET in a clinical setting, proposing a partnership with providers at EFCST. Martin recalls, “We jumped at the offer.”

“That was a great introduction to starting self-management within our affiliate,” said Martin, adding that in recent years they’ve also partnered with the University of Arizona PRC on a study of the Spanish-language version of MINDSET. As one participant put it, the program helped her to better manage her epilepsy by helping her understand that her seizure medication was causing certain side effects. “Thanks to MINDSET, I realized this and could discuss it with my doctor,” she said.



In 2017, with CDC funding, EFCST rolled out a second evidence-based self-management program called HOBSCOTCH (HOMe-Based Self-management and COgnitive Training CHanges lives). Developed by researchers at the Dartmouth College PRC, HOBSCOTCH is a one-on-one telephone-based intervention designed to improve memory and quality of life in adults with epilepsy through eight sessions held weekly. “We talk about what memory and thinking problems they’ve had, introduce a memory technique they can practice that week, and then review progress the week after,” said Martin, one of two certified HOBSCOTCH memory coaches on staff. “The program requires a commitment from participants, but it works—I’ve seen how much it helps people.”

Then there’s the MEW Network’s PACES (Program of Active Consumer Engagement in Self-management) and UPLIFT (Using Practice and Learning to Increase Favorable Thoughts) programs, both group-based interventions consisting of weekly meetings by telephone—from the safety and comfort of home. In PACES, participants learn coping and goal-setting strategies to improve their confidence and quality of life, while UPLIFT teaches participants skills for depression management, with hour-long sessions that teach how to challenge negative thoughts, solve problems, and practice mindfulness.

IMPACT

In 2020, EFCST provided over 90,000 services to more than 20,000 people across 79 counties in Texas. That includes clinical care for more than 1,000 patients and self-management support for dozens more. Results from the three MINDSET studies conducted with the Universities of Texas and Arizona indicate that both providers and patients find MINDSET to be helpful and effective in identifying patient self-management issues, increasing communication about strategies for improvement, and in fostering the long-term adoption of epilepsy self-management behaviors.



WHAT'S NEXT?

EFCST continues to pave the way for building more effective epilepsy self-management programs and services for people with epilepsy. Since 2019, the EFCST team and their colleagues at the University of Arizona PRC have been engaged in a 5-year study to enhance MINDSET with screening questions that could identify adults who would benefit from participating in one or more of the other EFCST-delivered MEW Network Programs: HOBSCOTCH, PACES, and UPLIFT. “Addressing the self-management needs of people with epilepsy has been a public health priority in epilepsy as long as I’ve been involved in the field,” said Rosales. “We’re delighted to be at the forefront of this important work both from the research standpoint and program delivery standpoint. Our patients and clients have so many needs, and these programs offer skills that they can use every day to improve their quality of life. We’re all in!”

Alongside its support for self-management, EFCST is working with the Texas chapter of the National Alliance on Mental Illness (NAMI) and Molina Healthcare system to improve the referral process for people with epilepsy to behavioral health care organizations. This additional CDC-funded effort aims to identify early signs of depression through regular screening of people with epilepsy, referrals to community partners, and epilepsy care training for behavioral health providers.

FIND OUT MORE

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To learn more, visit:

<https://managingepilepsywell.org/mindset>

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The findings and conclusions in this success story are those of the author(s) and do not necessarily represent the official position of the funding agencies or the Centers for Disease Control and Prevention (CDC).

