

TexCen Connects: Regional Communities

Provide personal outreach, education, and support to families affected by rare, chronic bleeding disorders in rural North Texas

Why it Matters

More than 400 affected families in rural areas across North Texas lack access to specialized treatments and support that can mean the difference between a life of well-being and productivity versus one marred by excruciating pain, joint damage, and life-threatening internal bleeding.

Many families may not even have a hospital or primary care provider in their county. 75% of the 254 counties in Texas are designated as Health Professional Shortage Areas and/or Medically Underserved Areas. This includes 64 counties without a hospital and 25 counties without a primary care physician.



Solution

Create a personalized cost-effective support network for families living more than 2 hours from Dallas-Fort Worth and educate local healthcare resources on how to provide help when needed.



Support and referral network

Develop a network of partners to support telemedicine, virtual and in-person education for families and rural healthcare providers, local mentor groups, travel to/from Hemophilia Treatment Center (HTC) appointments, and other needs. Partners will include Texas HTCs, Texas Rural Health Association, F. Marie Hall Institute for Rural and Community Health, UT Tyler East Texas Health Project, and other state and regional organizations.



Personal outreach, education and connections

Use known resources to find and reach patients and their families. Connect them to the support and referral network for access to personalized information and resources. Facilitate connections between affected families to share experiences, advice, and emotional support.



Training and education for local health provider resources

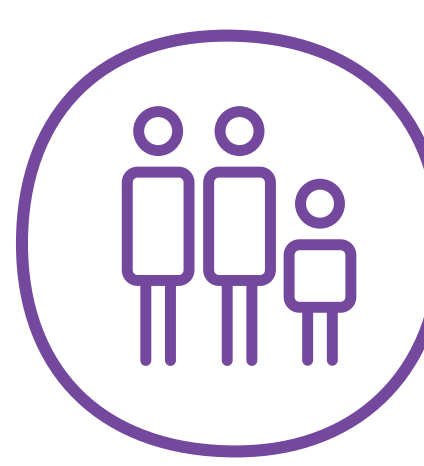
Leverage the partner network to train and educate local healthcare providers, school nurses and emergency responders.



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Impact

Goals and results for each program activity will be defined, including:



Identification of new families in four rural areas across North Texas



Number of in-person and virtual events and participation rates



Development of outreach programs based on surveys of patient needs/barriers



Targeted education of rural providers and use of HTC comprehensive care model



Identification and training of Regional Member Mentors



Creation and distribution of school nurse packets

