# Sickle Cell Association of Texas Marc Thomas Foundation



## THE NEED FOR SICKLE CELL SERVICES AND FUNDING IN TEXAS

The Sickle Cell Association of Texas Marc Thomas Foundation started in 1997 by Pastor Marc Thomas and his wife who wanted to advocate for families suffering from sickle cell disease. Pastor Marc Thomas suffered from sickle cell disease, pulmonary hypertension, congestive heart failure and wore oxygen 24 hours a day. He passed away from sickle cell disease at the age of 46 but his wife and daughter continue his legacy and mission.

#### Our Services

We currently provide services to 750 individuals with sickle cell disease and their families. We have three office locations: Austin, San Antonio and Houston.

- Case Management, Counseling, Certified Hemoglobinopathy Education, Transition Services, Care Coordination, Medical Home Placement, Free Sickle Cell testing, Scholarship Program, Emergency Financial Assistance, Outreach, Education and SOS Support Group Meetings
- Social Support Group Events
  - Christmas Parties
  - Walks
  - ► ESCAPE Retreat
- Camps for Special Needs Children
  - Camp Cell-A-Bration for children ages 6-14 with sickle cell disease
  - ► Camp Cell-A-Bration Next Level for transitioning teenagers ages 15-19









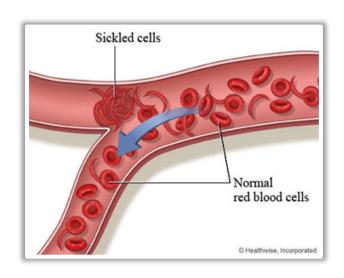
#### Sickle Cell Disease in Texas

There is an unprecedented need to continue providing services to sickle cell families across the state. In Texas, there are more than an estimated 300,000 people with sickle cell trait and many are unaware of it. Some studies suggest that it costs the economy over \$2 billion annually to care for sickle cell patients. Patients with adequate education, medical home placement and case management services can reduce these enormous costs.

#### Public Health Concern

In the Texas 1 in 12 African Americans have sickle cell trait and many are unaware that they are carriers. Sickle Cell affects not only African Americans, but Hispanics, Caucasians, Greeks, Italians, Asians and people of Mediterranean descent.

Individuals with sickle cell disease and their families suffer from financial limitations, mental illness, lack of insurance, access to care difficulties and plethora of disparities that reduces their quality of life.





# Please support sickle cell legislation, funding and services. If you have any questions, please email <a href="mailto:athomas@sicklecelltx.org">athomas@sicklecelltx.org</a> or call 512-458-9767



### Sickle Cell Disease

Sickle Cell Disease is the most common genetic blood disorder in the world and it affects the red blood cells. Healthy red blood cells are round and moves through blood vessels to carry oxygen to all parts of the body. With sickle cell disease the red blood cells become hard, sticky and resembles a C-shaped farm tool called a "sickle." The sickled cells die early causing a shortage of red blood cells and when clumped together, they become lodged in arteries causing severe pain known as a "pain crisis." Not only does sickle cell disease cause excruciating pain it causes: jaundice, stroke, organ damage, physical impairment, necrosis and early death. This chronic and life-threatening condition occurs when two parents, each having sickle cell trait passes both genes to their child causing sickle cell disease. This devastating diagnosis to new parents often creates feelings of guilt for being unaware of their sickle cell trait status and our agency provides a beacon of emotional and social support. Life expectancy is 40 years of age and there is no universal cure.

• Serving Sickle Cell Families in Texas Since 1997 • www.sicklecelltx.org