

Texas Sickle Cell Advisory Committee – Promoting Awareness of Sickle Cell Discussion Points
March 30, 2018

- Establish a State-wide Sickle Cell Collaborative
 - **Strongly consider as one of the two official strategies**
 - Incorporate vision of the **current** Sickle Cell Advisory Committee but additionally
 - broaden objectives
 - increase stakeholders
 - decrease redundancy
 - improve efficiency/effectiveness of silo outreach efforts
 - Models: [Louisiana Sickle Cell Commission](#), [Virginia Sickle Cell Awareness Program](#), [Indiana Sickle Cell Consortium](#), [Georgia Hemoglobin Disorders Coordinating Center](#), [California Sickle Cell Resources](#), [Sickle Cell Treatment Demonstration Program](#)
 - Encourage city/region-wide collaboratives (model: Houston Sickle Cell Collaborative)

- Initiate State-wide Sickle Cell Surveillance
 - **Consider as one of the two official strategies** (or make additional)
 - Expand/maximize/improve **current** Newborn Screening “Long-Term Follow-up” efforts
 - Incorporate with planned state-wide (and city-wide) syndromic surveillance efforts
 - Most effective way is to partner with state CMS agencies (would be a symbiotic relationship, as **they are already assessing** burden of sickle cell care)
 - Model: [Sickle Cell Data Collection Program](#) (California and Georgia), Louisiana, Missouri, etc.

- Partner with **current** Community Health Worker Network improve healthcare access
 - **Consider as one of the two official strategies** (or make additional)
 - CMS-associated and other government-funded healthcare entities
 - Focus on outreach: 1) rural and underserved regions, 2) high utilization facilities
 - link patients to primary care ± hematology care

- Develop a State-wide Sickle Cell Campaign
 - **Consider as one of the two official strategies** (or make additional)
 - Employ services of a professional/graduate school-level marketing team
 - Timing (variable options): year/season-long vs. month-long (national awareness month)
 - Messaging dependent on focus/target population, e.g.
 - “Know Your Trait Status” College Campaign (**tie-in with NBS data** on rising trait/disease #s)
 - Awareness of new therapeutic options/research trials networks
 - Consider associating with another state-wide campaign (hydration, stroke, maternal mortality, newborn screening, etc.)

- Expand outreach of **current** Texas Health Steps (THSteps) [Sickle Cell Module](#)
 - Additional recommendation
 - Incorporate into mandated training for government-funded healthcare entities (specified personnel) and public school district personnel (nurses/coaches/counselors/teachers)
 - Encourage Community Health Workers to take module if working in areas that intersect with sickle cell population

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- Recommence and potentially re-purpose the **current/annual** Hemoglobinopathy Consultants meeting
 - Additional recommendation
 - Medical expert panel which promoted EB sickle cell guidelines and advised Texas HHS/DSHS (e.g. Newborn Screening Unit, THSteps Sickle Cell Module, etc.)
 - Can potentially be a sub-committee of future collaborative or remain a separate entity

- DSHS Sickle Cell Website Updates (in progress)
 - **Initiated during our tenure**
 - Additional recommendation: should be a routine task for Hemoglobinopathy Consultants or future Collaborative

- Sickle Cell Toolkit
 - **Initiated during our tenure**
 - Currently incorporated into website updates
 - Additional recommendation: have an electronic and hardcopy version of file which can be provided to various groups (community, schools, healthcare systems, etc.)