

# Highlights and Takeaways from Other State Sickle Cell Plans

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**PSCRC**

The Pacific Sickle Cell Regional Collaborative works to ensure that people with sickle cell disease receive quality care, no matter where they live or seek care.

# Sickle Cell in California

- ◆ ~ 7,000 persons living with SCD
  - Large population relative to other states
  - Small proportion of persons with chronic severe medical conditions
- ◆ 51% of patient population in LA County
  - Underserved (adults), low access to knowledgeable care
- ◆ 49% of patient population is dispersed, with varying access to care
- ◆ Most adults do not see a hematologist in any given year
  - Many also do not have reliable primary care

# Sickle Cell in California

- ◆ Newborn screening gets affected children reliably into care
- ◆ Pediatric care is excellent for the majority of children with SCD
- ◆ Excellent adult care in a small number of centers
- ◆ Medicaid expansion state (65-75% on Medi-Cal/CCS/GHPP)
- ◆ Stakeholder collaboration – drive to improve care and outcomes

# States with Plan

- ◆ Connecticut - Designing a Comprehensive System Across the Life Span: State Plan to Address Sickle Cell Disease and Trait (December 2007)
- ◆ Michigan - A Public Health Strategic Plan to Address Sickle Cell Disease Across the Lifespan 2015—2018 (October 2015)
- ◆ South Carolina - Sickle Cell Disease Study Committee Report to the General Assembly (June 2016), and associated assembly bill

# States with Statewide Initiative to Address SCD/SCT

- ◆ North Carolina – NC Sickle Cell Syndrome Program, statewide, centralized program providing medical and support services to children and adults (since 1973)
- ◆ Ohio – standards of care and service delivery for SCD for those providers receiving specific SCD funding
- ◆ Indiana – Consortium of care providers and support services
- ◆ New York – state legislation drafted but not passed

# HIGHLIGHTS FROM CT, MI, SC PLANS

# Education and Raising Awareness

- ◆ Public awareness about SCD and SCT
- ◆ 'Know your status' messaging
- ◆ School based education/awareness

# Transition/Empowerment

- ◆ Education
  - Children/teens with SCD
  - Care givers
  - Healthcare providers
  - Systemic/Healthcare system support for families and those with SCD
- ◆ Establishing 'agency'
  - Who is responsible for decision making? Providing information? Providing care?
- ◆ Understanding of ongoing health needs
  - How will disease change over the life course?



# Provider Shortage/Workforce Development

- ◆ Improve access to
  - Hematologic care for all
    - Practicing hematologists
    - Transportation/distance
    - Insurance/Medicaid coverage
  - Knowledgeable ED care
  - Knowledgeable sub specialty care
- ◆ Increase number of PCPs caring for SCD
  - Support and train those PCPs
- ◆ Increase clinical and cultural knowledge base for all those caring for those with SCD

# Psychosocial/Mental Health Support

- ◆ Access to psychosocial care and support
- ◆ Educational support for success
  - Secondary as well as K-12

# Day Hospitals

- ◆ Improving access to care
- ◆ Improving outcomes
- ◆ Lowering costs

# Research (SCD and SCT)

- ◆ Grants/awards to conduct research locally to improve care and outcomes
- ◆ Clinical trials
- ◆ Academic research

# State Infrastructure (the How)

- ◆ Surveillance (to describe need and then evaluate actions)
- ◆ Statewide office/coordinating center
- ◆ State system (GHPP?) dedicated to assuring quality care
- ◆ County or UC based SCD specialty clinics
- ◆ Reimbursement rates
- ◆ Academic (UC Med Schools) programs for training
- ◆ Trained CHWs and other support systems
- ◆ Systemic education