Maternal and Child Health Initiatives in Sickle Cell Disease

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Health Resources and Services Administration (HRSA)
Maternal and Child Health Bureau (MCHB)

Health Resources and Services Administration (HRSA)

- Expands access to comprehensive, high quality, culturally competent health care to medically underserved populations, including:
  - Low income
  - Uninsured
  - Isolated
  - Vulnerable
  - Special Needs Populations

Maternal and Child Health Bureau

In partnership with States, communities, public-private partners, and families:

- Provide national leadership for maternal and child health
- Promote environment that supports maternal and child health
- Strengthen health infrastructure and systems of care
- Eliminate health barriers and disparities
- Assure quality of care

Maternal and Child Health Bureau

- The MCH population includes all America’s pregnant women, infants, children, adolescents, and their families - including women of reproductive age, fathers, and children with special health care needs.

Division of Children with Special Health Care Needs

President’s New Freedom Initiative (2001)

Responsibility for developing community-based systems of care for children with special health care needs

Healthy People 2010 Objective 16-23

“Increase the proportion of States and territories that have service systems for children with special health care needs.”

Division of Children with Special Health Care Needs

Core Indicators:

- Family professional partnership
- Access to care through medical home
- Adequate insurance for children and youth
- Early and continuous screening
- Inclusive community systems
- Adolescent transition to adulthood and independence

Division of Children with Special Health Care Needs

National Survey of Children with Special Health Care Needs (2001) – System Components

● Family Partnership and Satisfaction	**Status: 57%**
● Access to Medical Home	**Status: 51%**
● Access to Affordable Insurance	**Status: 60%**
● Early and Continuous Screening	**Status: 52%**
● Easy Access to Community Based Services	**Status: 74%**
● Services to Transition to Adulthood	**Status: 6%**

Division of Children with Special Health Care Needs

- Two legislatively mandated sickle cell disease initiatives:
- **Sickle Cell and Newborn Screening Program**- Support community-based models of delivering SCD and SCD carrier counseling and follow-up and linkage to newborn screening and comprehensive system of care.
- **Sickle Cell Disease Treatment Demonstration Program** - Develop and establish mechanisms to enhance the prevention and treatment of sickle cell disease through the coordination of service delivery; genetic counseling and testing; bundling of technical services; training of health professionals; and other related efforts.

Sickle Cell Disease and Newborn Screening Program

Purpose

- enhance access to comprehensive care, including education and counseling, for newborns diagnosed with sickle cell disease (SCD) or as carriers, and their families
- develop partnerships among State Title V and State newborn screening programs, local community-based SCD support organizations, comprehensive SCD treatment centers, and community-based clinicians

Sickle Cell Disease Newborn Screening Program

- $4 million appropriated annually since 2002
- 17 demonstration projects in 14 states and the District of Columbia with grant awards of $185,000 per year for 3 years
- One National Coordinating and Evaluating Center funded at $750,000 per year
- New funding competition in 2008

Sickle Cell Disease Newborn Screening National Coordinating and Evaluation Center (NCEC)

Cooperative agreement with Sickle Cell Disease Association of America (SCDAA) to support the 17 grantees:

- Technical Assistance/Information Exchange
- Data Collection and Evaluation
- SCD Educational Materials Development
- Hemoglobinopthy Counselor Certification
- Partnership Building

Sickle Cell Disease Treatment Demonstration Program (SCDTDP)

- Authorized under Section 712 (c) of the American Jobs Creation Act of 2004, Public Law 108-357
- Purpose - Increase access to and the capacity/capabilities of primary health care providers to provide coordinated and comprehensive services for individuals and families with sickle cell disease and those who are carriers.

SCDTDP

- In Fiscal Year 2007 $1.88 million awarded:
  - 4 Regional Sickle Cell Disease (SCD) Treatment Demonstration Networks (TDN) funded @ $320,000 annually for 4 years
  - National Coordinating Center

Treatment Demonstration Networks

- Health Services, Inc - Montgomery AL
- Roseland Christian Health Ministries - Chicago IL
- Stedman-Wade Health Services – Wade NC
- University of Cincinnati - Cincinnati OH

Treatment Demonstration Networks - Activities

- Establishing coordinated care networks of primary care clinicians, specialty sickle cell providers, and community-based SCD support organizations.
- Establishing medical homes for SCD patients
- Creating SCD patient registries
- Implementing quality improvement measures
- Providing education and training to patients, families, and their health care providers

National Coordinating Center

Research Triangle Institute International (RTI) in partnership with Meharry Medical College & SCDAA serves as the National Coordinating Center through a contract.

NCC-RTI Activities

- Technical assistance/Information exchange
- Educational materials review and development
- Identification of performance measures and quality indicators
- Collection of data and analysis
- Identification of promising best practices and well-defined guidelines relative to prevention and treatment of SCD
- Development of partnerships and strategies for sustaining them

Regional Genetic Service and Newborn Screening Collaboratives

HRSA/MCHB funds 7 Regional Genetic Service and Newborn Screening Collaboratives and a National Coordinating Center to:

- Improve access to quality care and appropriate genetic expertise and information for individuals with heritable disorders and their families
- Enhance communication and collaboration among public health, individuals, families, primary care providers, and genetic medicine and other subspecialty providers

Regional Collaboratives and SCD

Community-based outreach projects

Pilot project: to study effectiveness of intervention modules for sickle cell disease (Georgia, North Carolina, Alabama, Florida)

- Utilizing partnerships with HRSA/MCHB funded sickle cell disease projects

National Newborn Screening and Genetics Resource Center (NNSGRC)

National Newborn Screening Information System (NNSIS) – designed to provide a secure, Internet based, real-time, information collection and reporting system for capturing state and territorial newborn screening information.

http://genes-r-us.uthscsa.edu

http://www2.uthscsa.edu/nnsis/

Thank You!

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