

Community-based Public Health Approach to Newborn Screening Follow-up for Sickle Cell Disease

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Baltimore, MD

THANK YOU

- **HRSA**
- **Grantees - 17**
- **Advisors, Consultants and Partners**
- **National Coordinating and Evaluation Center Staff**

HRSA NBS INITIATIVE - 1

- **In 2002, Sickle Cell Disease Association of America (SCDAA) & the Maternal and Child Health Bureau (MCHB) of HRSA began a joint 3-year effort entitled the National Sickle Cell Disease and Newborn Screening Program (SCD NBS)**

HRSA NBS INITIATIVE - 2

- **This program has so far addressed**
 - **Problems with newborn screening (NBS) follow-up efforts for sickle cell and other hemoglobinopathies (i.e., parent & provider education)**
 - **Partnership gaps**
 - **Insufficient documentation about the effectiveness of what is actually being done to improve follow-up of NBS**

HRSA NBS INITIATIVE - 3

- **Aim of the national SCD NBS is to:**
 - **Fund & support 17 community-based SCD organizations and their partners from across the U.S.**
 - **Enhance the follow-up component of State SCD screening programs &**
 - **Work on projects that provide SCD-related education, SCD carrier counseling, & support services**

HRSA NBS INITIATIVE - 4

- **Expectations/Requirements of Grantees:**
 - **Develop & maintain a collaborative relationship with their State's Title V & NBS programs & existing State sickle cell disease program**
 - **Develop & maintain an effective partnership between a community-based SCD organization and a local comprehensive sickle cell treatment center – apparent & in existence**

HRSA NBS INITIATIVE - 5

- **Expectations/Requirements of Grantees**
 - Collaboration with community-based primary care providers
 - Collaborate with the national SCD coordinating and evaluation center & fellow grantees for the purpose of
 - collecting & sharing information
 - standardizing education & counseling activities offered by the network of local, community-based projects

GRANTEES

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- **Sickle Cell Disease Association of Dallas**
- **Sickle Cell Disease Association of Piedmont**
- **Sickle Cell Foundation of Georgia**
- **Sickle Cell Disease Foundation of California**
- **Sickle Cell Disease Association of Illinois**
- **Arkansas Newborn Sickle Cell Program**

GRANTEES

- **Hospital for Special Care**
- **Lincoln Hospital Department of Pediatrics**
- **Broward County Hospital District**
- **Brookdale University Hospital and Medical Center**
- **D.C. GAPS, Howard University
Department of Pediatrics and Child Health**

GRANTEES

- **St. Jude Children's Research Hospital**
- **Children's Hospital & Research Center at Oakland**
- **Odessa Brown Children's Clinic, NWSCC**
- **Children's Hospital of Pittsburgh**
- **Michigan Department of Community Health**
- **Hawaii Department of Health**

**Grantee
Principal Requirements
(Endpoints)
from the Guidance**

Grantees Must Demonstrate (1)

- **A collaborative relationship with their State's Title V and newborn screening programs and, if there is one in existence, their State's sickle cell disease program**
- **An effective partnership between a community-based sickle cell disease organization and a local comprehensive sickle cell treatment center (This partnership should be apparent and in existence)**

Grantees Must Demonstrate (2)

- **A willingness to collaborate with community-based primary care providers**
- **A commitment to collaborate with the NCEC funded by this initiative and fellow grantees to collect and share information, and to standardize education and counseling activities offered by the network of local, community-based projects**

Performance Measures

GRANTEES

Performance Measures

- **PM 07 - Provide National Leadership for MCHB**
 - Promote family participation in care
 - **Measure:** The degree to which MCHB supported programs ensures family participation in program and policy activities
- **PM 10 - Eliminate Health Barriers & Disparities**
 - Develop and promote health services and systems of care designed to eliminate disparities and barriers across MCH populations
 - **Measure:** The degree to which MCHB supported programs have incorporated cultural competence elements into their policies, guidelines, contracts and training.

Overview

National Coordinating and Evaluation Center (NCEC)

NCEC STAFF

- **Joseph Telfair, DrPH, MSW/MPH, Project Director**
- **Sonya Ross, Associate Director**
- **Nancy Callahnan, MS, CGC, & Genetics team, Health Education and Communication Specialist**
- **Eileen Miller, Project Manager**
- **Claudine Williams, MA, Project Evaluator (former)**
- **Natasha Thomas, Project Associate**
- **Teneshia Richards, Business Manager**

Performance Measures

NCEC

Performance Measures

- **PM 03** - Provide National Leadership for MCHB
 - Strengthen the MCH knowledge base and support scholarship within the MCH community
 - **Measure:** The percent of completed MCHB supported projects publishing findings in peer-reviewed journals
- **PM 07** - Provide National Leadership for MCHB
 - Promote family participation in care
 - **Measure:** The degree to which MCHB supported programs ensures family participation in program and policy activities

Performance Measures - NCEC

- **PM 10 - Eliminate Health Barriers & Disparities**
 - Develop and promote health services and systems of care designed to eliminate disparities and barriers across MCH populations
 - **Measure:** The degree to which MCHB supported programs have incorporated cultural competence elements into their policies, guidelines, contracts and training.

2005-2008 OUTCOMES

OUTCOMES

- 1. Increase knowledge about SCD for families with babies identified with SCD, as carriers of SCD or other hemoglobinopathies, and of their providers who are served by the HRSA funded SCD community-based programs**
- 2. Strengthen partnerships between HRSA funded SCD community-based programs and partners**
- 3. Improve SCD newborn screening and carrier follow-up activities of the HRSA funded SCD community-based programs**

NCEC
Goals and Planned Activities –
Content Area and Application

2005-2008

Target Populations

- There are one primary and two secondary target populations to which NCEC efforts, in collaboration with the community-based grantees and other partners, will be directed
 - **Primary**: The grantees of the funded SCD NBS programs
 - **Secondary**: The community of NBS programs, healthcare and local service providers
 - **Secondary**: Families and newborns who are provided these services

Goals and Activities

- **Came out of a Review of the work of the NCEC in Years 1 and 2**
- **Builds on what NCEC has developed in the last five years**
- **Addresses intent, performance measures and outcomes for the grantees, the NCEC and the overall Newborn Screening Initiative**

Goals and Activities (1)

- **Content Area: Materials Development**
- **Application: Develop, assess, & disseminate educational materials -providers, families, & clients w SCD**
 - **Summer 2007** - Materials Toolkit for SCT completed, reviewed by MARAC and currently being reviewed by HRSA
 - **Summer 2007** - Materials Toolkit for SCD in process by Genetics Team
 - **Summer 2007** - Welcome Kit for families of newborns with SCD in process
 - Concept completed by health literacy consultant
 - Content completed by Genetics Team
 - Focus groups of families and providers scheduled for October 2007

Goals and Activities – (2a)

- **Content Area: Database Development**
- **Application: Collaborate w grantees to develop & implement common (minimum) database [project] (MDP) & means of evaluation for the NCEC & grantees**
 - **Data Development and Evaluation**
 - **Grantee training completed - April – May 2007**
 - **MDP available online - July 2007**
 - **Five grantees have uploaded data – August 2007**
 - **Technical assistance being offered**
 - **IRB approval for remaining grantees forthcoming but slow**

Goals and Activities – (2b)

- **Data Development and Evaluation (cont')**
- **Needs and assets survey completed and available online – May 2007**
- **Steering Committee trained in its use during WebEx presentation – June 2007**
- **Client satisfaction survey distributed to grantees – June 2007**
- **To date, 25% of the those distributed have been returned**

Goals and Activities (3)

- **Content Area: Counselor Certification**
 - **Application: Develop, implement, and evaluate a National Counselor Certification Program**
 - **Summer 2007 – Two curricula developed and being reviewed by stakeholders**
 - **Summer 2007 – Survey to validate domains, activities and tasks pilot tested by stakeholders**
 - **Directory of SCDA member's staff who provide counseling compiled**
 - **Fall 2007 - Further validation of domains, activities and tasks will be completed by identified SCDA counselors**

Goals and Activities (4)

- **Content Area: Partnership Building**
- **Application: Assist grantees in partnership - building activities w other sickle cell orgs at both the state/local & national levels**
 - **Spring 2007 - NCEC conducted site visits with two grantees to facilitate and improve the use of partnerships among other issues**
 - **Face to Face Steering Committee Meeting focused on sustainability and partnership building – May 2007**
 - **Grantees shared their unique partnerships and funding sources**

Goals and Activities (5)

- **Content Area: Support & Information Exchange (TA)**
- **Application: Engage in information exchange/TA & support activities with grantees**
 - **Spring 2007 - Needs and Assets Survey available online**
 - **Spring 2007 - Writing group formed and subject/title chosen**
 - **“Emerging Best Practices” and Lessons Learned**
 - **Four writing leaders chosen**
 - **All those interested will have an opportunity to make substantive contributions**

METHODS

METHODS

- **As part of this effort, the National Coordinating and Evaluation Center (NCEC) methods focuses on**
 - **Collaborating with the 17 grantees in capacity building efforts (e.g., technical assistance, training and problem-solving),**
 - **Documenting best practices (current and planned efforts)**
 - **Evaluating the outcomes of the total efforts of the SCD NBS program.**

Formative efforts include

- **Qualitative** - open-ended survey questions & individual interviews, trainings, consultations and site visits
- **Quantitative** - closed-ended & checklist formatted survey questions & secondary data documents & database development
- **Assessment tools** designed specifically for the SCD NBS project – Minimum Data Project, Needs/Asset Surveys and Self-Assessment

Expected and Realized Outcomes of NCEC Work- To-Date

Expected and Realized Outcomes - 1

- **Historic opportunity to test assumptions about use of targeted resources – education, counseling, care coordination - to assure and improve NBS and follow-up services for persons with SCD and their families**
- **Provide the evidence for multi-institutional collaboration to promote and educate NBS and follow-up for providers and the general public**

Expected and Realized Outcomes - 2

- Document what works and does not work ('Best Practices') within partnerships among:
 - State Title V and newborn screening programs,
 - Community-based SCD organizations
 - Comprehensive sickle cell treatment centers
 - Community-based primary care providers
- Development of a model certification program for SCD counseling and education
- Use of technology (e.g., web-site) to provide a community forum between clients, families, health care professionals for the identification and prioritization of issues of importance to the SCD community

**Future Implications of
National NBS Initiative
for the
SCD Community**

Future Implications 1

- **‘Best Practices’ and ‘Lessons Learned’ can influence decisions for program development, advocacy efforts, treatment and the delivery of services**
- **Reinforce the need to document and assess work done – Template, Database**
- **Have a better understanding of what it takes to engage and educate providers and the general public about NBS for SCD and related issues**

Future Implications 2

- Reinforce the need for SCDA and similar organizations to develop and implement a means or infrastructure for evaluation and research activities
- Maximize the opportunity to improve the collaborative partnership with similar organization and groups
- Reinforce the need for SCDA and similar organizations to recognize the contribution of clients, community-based organizations and groups as partners in the achievement of successful outcomes of SCD evaluation and research
- Local, State and National partners are critical

Questions And Discussion