

under OMB No. 0920-0428). Applicants must use the appropriate Catalog of Federal Domestic Assistance (CFDA) number 93.110 and the title, "Sickle Cell Disease and Newborn Screening Program," when requesting application materials. The CFDA is a Government-wide compendium of enumerated Federal programs, projects, services, and activities that provide assistance. All applications should be mailed or delivered to: Grants Management Officer (MCHB), HRSA Grants Application Center, 901 Russell Avenue, Suite 450, Gaithersburg MD; Telephone: 1-877-HRSA-123 (477-2123); E-mail: hrrsagac@hrrsa.gov.

HRSA expects to begin accepting grant applications on-line on July 14, 2003. The automated application process should be faster, easier and better for applicants and for HRSA. We encourage you to take advantage of this new option. Check <http://www.hrrsa.gov/grants> to see which HRSA programs are accepting on-line applications.

FOR FURTHER INFORMATION CONTACT:

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mpuryear@hrrsa.gov (for questions specific to project activities of the program, program objectives, or the Letter of Intent described above); and Jacquelyn Whitaker, 301-443-1440; email, jwhitaker@hrrsa.gov (for grants policy, budgetary, and business questions).

SUPPLEMENTARY INFORMATION:

Program Background and Objectives

Sickle cell disease (SCD) is an inherited red blood cell condition characterized primarily by chronic anemia and periodic episodes of pain. In affected individuals, the abnormal red blood cells break easily and clog blood vessels to block blood flow to organs and tissues. This process results in anemia, periodic pain episodes, and ultimately can damage tissues and vital organs and lead to increased infections and early death. In the United States, most cases of SCD occur among people of African ancestries. People of Mediterranean, Middle Eastern, and Indian background are also affected. It is estimated that more than 2 million Americans have the sickle cell trait and over 70,000 have the disease. Annually, approximately 1,000 newborns are identified with the disease through state newborn screening programs.

Early diagnosis of SCD is critical so that children who have the condition can receive proper interventions. Newborn screening for SCD followed by parental health education, enrollment in

comprehensive care, initiation of penicillin prophylaxis and anti-pneumococcal vaccination within the first two months of life can prevent death from severe infections.

The Federal MCHB has long recognized the significance of SCD. In the mid 1960s, MCHB developed and disseminated SCD educational materials nationally. Following passage of the National Sickle Cell Anemia Control Act in 1972, MCHB, with initial funding from the National Institutes of Health (NIH), provided support for community-based sickle cell clinics to conduct testing, counseling, and education. In the mid 1980s, the Federal MCHB supported the development and implementation of State newborn screening programs for SCD. By 1990, 30 States and jurisdictions had implemented programs with direct Federal support. Although most States and jurisdictions currently have Statewide screening programs, a 1987 Consensus Development Conference on Newborn Screening for Sickle Cell and Other Hemoglobinopathies recommendation for universal screening has not been realized.

In FY 2002, MCHB funded 15 community-based grants and one cooperative agreement through its Sickle Cell Disease and Newborn Screening Program. These one-year community-based awards were established to enhance follow-up services for infants who screen positive for SCD or sickle cell trait and support community-based efforts to provide SCD-related education and counseling. For FY 2003, similar awards will be made for this purpose.

All State SCD screening programs include a follow-up component. Some, however, fall short of the guidelines recommended by the Council of Regional Networks for Genetic Services (CORN). There are infants with SCD who do not enter into appropriate programs of comprehensive care and do not receive the requisite interventions. Further, follow-up of infants with sickle cell trait or who are carriers is sub-optimal. While the benefit of carrier notification leads to increased knowledge for the affected infant's family, problems of misunderstanding (infant with the trait perceived as defective), stigmatization, and issues of paternity can also result from carrier notification. It is thus imperative that trait notification and counseling be undertaken with sensitivity and accuracy. In many State SCD programs, parents are notified of the carrier infant's abnormal test results but are left on their own to seek education, genetic counseling, and testing. Many parents

do not receive counseling and testing. The educational component of the SCD program is just as important as the follow-up. Patients and families need to remain well informed and be empowered as active participants in service delivery. State SCD programs need to enlist partners in this effort, including primary care providers, subspecialists, and community-based support organizations. In some communities, the staff of the community-based organization can make the initial contact with the affected family and maintain subsequent contact and provide support and education.

Authorization

Section 501(a)(2) of the Social Security Act (42 U.S.C. 701(a)(2)).

Purpose

The purpose of the Sickle Cell Disease and Newborn Screening Program is to support the comprehensive care for newborns diagnosed with SCD or trait and their families, relying on partnerships among the State Title V and newborn screening programs, community-based SCD organizations, comprehensive SCD treatment centers, and community-based primary care professionals. Specifically, the program will enhance the follow-up component of State SCD screening programs and support community-based efforts that provide hemoglobinopathy counseling, SCD-related education, and support services.

Project 1—Through a cooperative agreement, a national SCD organization will partner with families, community-based SCD organizations, health care professionals, State agencies including State Title V and newborn screening programs, and MCHB and its National Newborn Screening and Genetics Resource Center (NNSGRC.) It will serve as a national SCD coordinating center, to coordinate the implementation of the community-based SCD projects funded by this initiative and provide a community forum to identify and prioritize issues of importance to the SCD community.

Project 2 "The grant funded community-based SCD projects will rely on partnerships between the community-based SCD organizations, State Title V and newborn screening programs, comprehensive sickle cell treatment centers, and community-based primary care professionals to provide support including counseling and education to infants screened positive for SCD and trait and their families; as well as participate in a cooperative relationship with the