

(2) CED/Distance Learning, (301) 443-0392

Program Contact E-Mail:

(1) Continuing Education and Development, *drule@hrsa.gov*

(2) CED/Distance Learning, *afavors@hrsa.gov*

HRSA-04-055 Genetic Services Projects: Delivery of Genetic Services (GSGE) and Regional Newborn Screening and Genetics Collaboratives (GSRC)

Legislative Authority: Social Security Act, Title V, 42 U.S.C. 701.

CFDA: 93.110.

Purpose: The purpose of this grant activity is to fund two separate initiatives to establish demonstration projects to address issues confronting State newborn screening and State Title V genetics programs. These initiatives will provide models, best practices, and dissemination strategies for ensuring optimal follow-up and management for children identified with heritable conditions by helping to translate genetic technological advances into practice.

Initiative 1—Regional Newborn Screening and Genetics Collaboratives

The purpose of this grant activity is to establish demonstration projects that enhance and support the newborn screening and genetics service capacity of State Title V programs. The projects will reflect partnerships among State programs, medical homes, families, and tertiary care centers. The projects will focus on ensuring optimal follow-up and management for children identified with heritable conditions by helping to translate genetic technological advances into practice. They will also undertake a regional approach toward addressing the maldistribution of genetic resources. The initiative will establish Collaboratives to: Serve as regional focus of genetics expertise for the subspecialty care and treatment and management of children identified with heritable disorders by newborn screening; Demonstrate partnerships with multiple state newborn screening and Title V programs within a region, modeling a regional approach toward facilitating access to the genetics expertise that providers and families need to diagnose and manage children identified with heritable disorders; Provide information, educational resources, technical assistance, and support to the medical homes within the region in the treatment and management of children identified with heritable disorders by newborn screening, as well as to the families of the children identified with heritable

disorders in the region. This will be done by: Utilizing innovations in communication and telehealth medicine; Demonstrating partnerships with existing comprehensive care programs to provide genetics expertise; Demonstrating the ability to offer technical assistance to State newborn screening and Title V programs served by the region; Assessing the long term health outcomes of children identified by newborn screening in this region and the clinical validity and utility of this regional approach; and Addressing issues related to the incidence of heritable conditions identified by newborn screening in the region. Funds available: \$2,000,000 for 4 cooperative agreements. The cooperative agreements will be funded for five years, subject to the availability of funding for years 2 through 5 and satisfactory grantee performance.

Initiative 2—Delivery of Genetic Services

The purpose of this grant activity is to establish 5 separate demonstration projects to examine genetic service issues such as service delivery and capacity, developing communities of practice for systems integration, quality of services, genetic literacy, education and awareness and the multiple social and ethical issues that have emerged from the use of new and evolving genetic technologies within these programs. All projects must consider the complexity of the public health and health care delivery systems. Applications may address Projects 1–5. Funds available: \$1,000,000 for 5 cooperative agreements. The cooperative agreements will be funded for two years, subject to the availability of funding for the second year and satisfactory grantee performance.

- One project will identify strategies and develop materials and a model that identifies and measures quantifiable performance criteria for newborn genetic screening programs. Issues such as expanded newborn screening, missed infants, false positive results, and delayed diagnosis will be addressed—Project 1.

- One project will identify strategies and develop materials and a model that utilizes a consumer-based family history tool to increase awareness about genetics—Project 2.

- One project will identify strategies and develop materials and a model to evaluate existing data and recommend and weight priorities on health and economic value of genetic services, including genetic testing, education and counseling to provide important cost,

health outcomes, and quality of care data—Project 3.

- One project will identify strategies and develop materials for addressing the ethical social issues surrounding the use of new and emerging technologies, the current models for delivering genetic tests and other genetic services—Project 4.

- One project will establish a resource center for developing a community of practice model for Genetic Service Branch's Best Practices in the Integration of Newborn Metabolic Screening Programs with Other Public Health Programs. The purpose of this resource center is to develop and implement policy initiatives related to achieving policy that supports integrating newborn metabolic screening programs with other public health programs and the health care delivery system. Components of the policy include definitions of integration, core function specification, standards of practice, and indicators to monitor and measure progress and outcomes. Direct involvement from a variety of public health programs and support functions, health care providers, community members, and families will be necessary for success because of the multiple, critical roles they play in the health of a newborn—Project 5.

Federal Involvement: The scope of federal involvement with respect to all of the cooperative agreements is included in the application kit.

Eligibility: As cited in 42CFR Part 51 a.3(a) any public or private entity, including an Indian Tribe or Tribal organization (as those terms are defined in 25 U.S.C. 450(b)) is eligible to apply for Federal Funding.

Review Criteria: Final review criteria are included in the application kit.

Estimated Amount of this Competition: \$3,200,000.

Estimated Number of Awards: 9.

Estimated Project Period: 5 years for Priority 1 projects (Regional Newborn Screening and Genetics Collaboratives-GSRC) and 2 years for Priority 2 projects (Delivery of Genetic Services-GSGE).

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Application Availability: October 15, 2003.

Letter of Intent Deadline: December 1, 2003.

Application Deadline: January 9, 2004.

Estimated Project Start Date: July 1, 2004.