

# **Application Guidance Competing New Proposals**

**CFDA: #93.110**

**Program Code: ISNSS**

**Program Announcement: HRSA-03-051**

**Fiscal Year 2003: Promoting Integration of State Health Information Systems  
and Newborn Screening Service Systems for Monitoring and Ensuring  
Quality Services to Newborns and Children With or At Risk for Heritable  
Disorders – Cooperative Agreement**

**Application Due Date: December 3, 2002**

**Special Projects of Regional and National Significance  
Genetic Services Branch/Division of Services for Children with Special Health Needs  
Office of Data and Information Management  
Maternal and Child Health Bureau  
Health Resources and Services Administration  
Department of Health and Human Services**

**NOTE: THE NECESSARY APPLICATION FORMS ARE ENCLOSED WITH THIS  
DOCUMENT AS PART OF THE APPLICATION.**



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## **SECTION ONE: Program Background, Fiscal Year 2003 Joint Program Initiative, Maternal and Child Health Bureau Requirements**

### **1.A. MATERNAL AND CHILD HEALTH BUREAU**

#### **Background**

The mission of the Maternal and Child Health Bureau (MCHB) is to improve the health and well-being of all of America's pregnant women, infants, children, adolescents and their families, including women of reproductive age, fathers, persons with hemophilia, and children with special health care needs with specific focus on individuals and families with low income levels, those with diverse racial and ethnic heritages and those living in rural or isolated areas without access to care.

To achieve its mission, the Bureau places the highest priority on integrating personal health care and public and private health services to establish a community system of comprehensive services that is family-centered, culturally competent and integrated with education, social services, mental health and family support programs.

With the Omnibus Budget Reconciliation Act (OBRA) of 1989, Public Law 101-239 amended Title V of the Social Security Act to extend the authority and responsibility of MCHB to fully address the needs of all children. OBRA '89 refocuses the mission of the State Programs for Children with Special Health Care Needs (CSHCN) under the Maternal and Child Health Services Block Grant, to provide leadership in building and promoting a community-based system of services that is family-centered, comprehensive, coordinated and culturally competent.

This mission is also reflected in *Healthy People 2010*, which includes an objective to have service systems for CSHCN. The purpose of this focus on systems development is to assure that CSHCN and their families have access to appropriate, adequate and timely services. The Bureau, through the Division of Services for Children with Special Health Needs (DSCSHN), continues to carry forward its mission of assuring the health of CSHCN and their families. DSCSHN developed a 10 year action plan to achieve that mission.

Significant components of the *10-Year Action Plan to Achieve Community-Based Service Systems for Children and Youth with Special Health Care Needs and Their Families (2010 Express)* are now part of the President's *New Freedom Initiative*, a major activity across Federal agencies to increase community integration for people of all ages with disabilities (<http://www.hhs.gov/newfreedom/final/hhs.html> see Chapter III.III.C). Because children with heritable conditions identified through newborn screening and other points of early identification are a subset of CSHCN, achievement of the *2010 Express* will improve newborn and genetic screening systems and services.

The six core goals of the *New Freedom Initiative* are:

1. Development of community-based systems of services that are inclusive of CSHCN and their families, where substantial decision-making authority is devolved from the federal government to the States to the communities.
2. Recognition that families are the ultimate decision-makers for their children and encouragement of participation in making informed decisions.
3. Development of standardized elements of the medical home for CSHCNs. In addition, the agency will develop and disseminate models of the medical home, and provide additional training resources to primary care professionals to develop medical homes.
4. Review of the variety of reimbursement mechanisms that impact CSHCN.
5. Through the Maternal and Child Health Block grant (Title V of the Social Security Act), and the Newborn Genetics Program (Title XXVI of the Child Health Act), expansion and strengthening of newborn screening systems and promote ongoing screening of CSHCN (incorporating EPSDT into the medical home concept).
6. Ensuring that youth with special health care needs receive the services necessary to transition to all aspects of adulthood, including from pediatric to adult health care, from school to employment and to independence.

Through these programmatic efforts, the MCHB will significantly influence the way services are provided to CSHCN and their families.

## **1.B. GENETIC SERVICES BRANCH/DIVISION OF SERVICES FOR CHILDREN WITH SPECIAL HEALTH NEEDS**

### **Background**

The Genetic Services Branch (GSB) is located in the Division of Services for Children with Special Health Needs of the Maternal and Child Health Bureau in the U.S. Department of Health and Human Service's Health Resources and Services Administration (HRSA). The GSB facilitates health promotion through early identification of heritable conditions, the development of comprehensive, culturally competent, family-centered genetic services, and an understanding of how genetics affects peoples' health.

Genetic services include a broad range of clinical and public health activities, such as individual and community assessment; genetic and newborn screening and counseling for heritable conditions; measuring susceptibility and prevalence of gene-related conditions that result from specific environmental exposures; and helping individuals with genetic conditions manage their health. Currently, these and other services are provided in a variety of community-based health care settings such as community health clinics, academic health centers, public health departments, public and private laboratories, and by private health care providers.

Through Title V of the Social Security Act, the Federal government's Maternal and Child Health (MCH) program began providing national leadership and support to States to develop genetic services capability long before there was a legislative mandate for a Federal genetic services program. This included the support of child development clinics in the 1950s and State newborn screening programs for metabolic disorders in the early 1960s. By the mid-1960s, the MCH program was also supporting biochemical and cytogenetic laboratory training programs and university affiliated programs to provide broad interdisciplinary training in the diagnosis and management of individuals with disabilities or mental retardation.

The 1972 Sickle Cell Anemia Control Act was the first Federal legislation concerned with genetic disorders. The National Institutes of Health (NIH), which was responsible for implementing the Act, transferred funds under this authority to the MCH program to develop community-based sickle cell education, screening, and counseling services.

In 1978, the Federal MCH program, through the National Genetic Disease Act (Title XI of the Public Health Service Act), began to build and improve genetic services at the State level by providing funding for statewide genetic services programs. It took 12 years, until 1990, for all 50 States, the District of Columbia, Puerto Rico, and the Virgin Islands to become participants in this Federal grant program activity. Federal funding to develop and improve statewide genetic services programs was provided with the understanding that States would continue these programs when Federal support ended. Today, all States have taken over this responsibility, with the scope of services available varying from State to State.

The GSB, through grants, cooperative agreements, contracts, and partnerships, has implemented projects in the following program areas:

- Public health infrastructure for the incorporation of genetic information and technology
- Emerging issues and technologies in genetics and newborn screening
- Training and education in genetics for health professionals
- Consumer initiatives and genetic literacy for the public
- Community genetic services, such as the National Hemophilia Program

### **Mission**

The mission of the GSB is to facilitate the early identification of individuals with heritable conditions and integrate them into systems of care that are comprehensive, accessible, available, affordable, acceptable, population and community-based, culturally appropriate and family-centered and to increase knowledge of the genetic contribution to health and disease upon which services are developed.

### **Goals**

These programs encourage the integration of various types of Federal, State, and community funded genetics services into systems of care that are responsive to the individual needs of the

people being served. The GSB works toward several goals that are part of this overarching mission. These goals are to:

- Strengthen and expand newborn screening programs, and nurture partnerships among them and existing State and community systems of care for CSHCN
- Examine emerging issues and technologies in the field of genetics and newborn screening and identify their financial, ethical, legal, and social implications
- Improve the public's "genetic literacy." Genetic literacy includes knowing about benefits, risks, and limitations of genetic screening and testing, as well as the implications of genetic information
- Help health care providers, social service professionals, and public health officials accurately communicate benefits, risks, and limitations of genetic screening and testing, as well as help them accurately interpret and properly use this genetic information in their practice
- Support the National Hemophilia Program and showcase it as a model for health care providers serving populations of all ages with special health care needs
- Provide national leadership on expanding and enhancing genetic services for the United States by building on the collective experience of the maternal and child health community

Overall, grants through the GSB are expected to:

- Improve follow-up rates for newborns with genetic conditions such as sickle cell disease that are identified by States' newborn screening programs
- Enhance compliance with treatment regimens and expand preventative care in areas affecting parenting skills and transitions to adult self-care
- Develop formal partnerships between providers and statewide systems of care
- Improve long-term outcomes for children with medically complex genetic disorders, such as cystic fibrosis and sickle cell disease, by facilitating the identification of a medical home for every child
- When appropriate, develop treatment protocols for children with metabolic and other genetically based conditions
- Expand screening resources for, and increase public awareness of, genetic medicine and establish training programs for health care and other types of service providers
- Collect standardized outcome data on morbidity and mortality in infants with genetic conditions detected by State screening programs

In addition, the Branch strives to develop programs that assure genetic screening will be done with appropriate counseling, and that such screening is accompanied with proper and timely interventions.

## 1.C OFFICE OF DATA AND INFORMATION MANAGEMENT

### Background

Created in 1999, the Office of Data and Information Management (ODIM) provides national leadership in the identification and analysis of data needs and the utilization and implementation of a data strategy and program focusing on the promotion of health and prevention of disease among women of reproductive age; infants, children, adolescents and their families with special emphasis on the development and implementation of family-centered, comprehensive, care-coordinated, community-based and culturally competent systems of care for such population.

### Mission

ODIM's mission is to be a national leader in advancing the scientific knowledge base in maternal and child health by conducting, promoting, and sponsoring data utilization and analysis which fosters the health of the maternal and child health population by reducing health disparities, and improving the health care system in general and the programs of the MCHB, in particular. ODIM is further committed to building the capacity of State and local health departments to use data effectively, as well as developing and enhancing the skills of the present and future generation of MCH leaders, and support the use of scientific data and methods to effectively guide programs and policies for the improvement of maternal and child health in the United States. ODIM strives to collaborate with the Divisions of HRSA, other Federal entities, academic institutions and other public/private organizations dedicated to improving maternal and child health through research and/or data capacity building particularly at the local level.

### Data Capacity Building Grant Program

ODIM has awarded Data Utilization and Enhancement Grants/Cooperative Agreements (DUE) (FY 2001-2002) to States to build linkages between data sets, such as birth and Medicaid files, to provide detailed information for addressing State maternal and child health issues. Federal support for these efforts will be continued with the award of Data Capacity Building Grants (FY 2003-2005). These grants will provide support to States as they develop Innovative Models to improve their data capacity. This effort may involve building the "next generation" of State MCH data systems, through data linkages or data integration; or re-engineering MCH-related vital records. ODIM will also continue to work with States to build data capacity.

## 1.D. FISCAL YEAR 2003 JOINT PROGRAM INITIATIVE

This guidance is for a joint program initiative of the Genetic Services Program and the Office of Data and Information Management for Fiscal Year 2003: **Promoting Integration of State Health Information Systems and Newborn Screening Service Systems for Monitoring and Ensuring Quality Services to Newborns and Children With or At Risk for Heritable Disorders.**

An increased demand for coordinated, continuous, comprehensive, community-based and culturally competent health and related services for newborns and children with or at risk for heritable disorders necessitates the development, enhancement and ongoing support of infrastructure building services to include information systems that are comprehensive, are integrated, and facilitate data transfer.

Conversely, as data systems proliferate, become more complex, and are expected to communicate with an increasing number of external portals, it is crucial that they meet certain common standards for efficiency of communication and cost-effectiveness of operations.

It is for these reasons that the MCHB Genetic Services Program in the Division of Services for Children with Special Health Needs and the MCHB Office of Data Information and Management are collaborating to develop this joint program initiative. Representatives from each of the aforementioned MCHB Offices will serve as co-project officers for each cooperative agreement.

See **Attachment “A”** to this guidance for further description and background information on the cooperative agreements to be funded under this announcement.

#### **Cooperative Agreement – The Federal Role**

Under the terms of this cooperative agreement, in addition to the required monitoring and technical assistance, Federal responsibilities will include: 1) participation, as appropriate, in meetings conducted during the period of the cooperative agreement; 2) ongoing review of activities and procedures to be established and implemented for accomplishing the proposed project; 3) review of project information prior to dissemination; 4) review of information on project activities; 5) assistance with the establishment of contacts with Federal and State agencies, MCHB grant projects, and other community-based contacts that may be relevant to the project’s mission and referrals to these agencies; and 6) assistance in the establishment of State, Federal, and community partnerships, collaboration, and cooperation that may be necessary for carrying out the project.

#### **Notice of Intent to Submit an Application**

If, after reviewing the program guidance and related materials in the application kit, you intend to submit an application, please see **Attachment “B”** of this guidance for directions on how to notify MCHB of your intent to submit an application. **Notice of intent to submit an application should be submitted to MCHB by September 30, 2002.**

## **1.E. POLICY REQUIREMENTS**

### **Healthy People 2010**

All grants under MCHB's programs further the agenda for *Healthy People 2010*; a DHHS-led national activity for setting priority areas for all HRSA funded programs. Copies of the *Healthy People 2010* documents can be obtained through the Superintendent of Documents:

- Order Online: <http://bookstore.gpo.gov/>
- Phone: (202) 512-1800 (DC Metro area), 866-512-1800 (toll-free)
- Mail orders to: Superintendent of Documents  
P.O. Box 371954  
Pittsburgh PA 15250-7954
- Order inquiries via e-mail: [gpoaccess@gpo.gov](mailto:gpoaccess@gpo.gov)

### **Special Concerns**

HRSA's Maternal and Child Health Bureau places special emphasis on improving service delivery to women, children, youth, individuals, and families from communities with limited access to comprehensive care. In order to assure access and cultural competence, it is expected that projects will involve individuals from the populations to be served in the planning and implementation of the project. The Bureau's intent is to ensure project interventions are responsive to the cultural and linguistic needs of special populations, services are accessible to consumers, and the broadest possible representation of culturally distinct and historically under-represented groups are supported through programs and projects sponsored by the MCHB. This same special emphasis applies to improving service delivery to CSHCN.

### **Evaluation Protocol**

All maternal and child health discretionary grant/cooperative agreement projects are expected to incorporate a carefully designed and well-planned evaluation protocol capable of demonstrating and documenting measurable progress toward achieving the project's stated goals. The protocol should be based on a clear rationale relating the grant activities, project goals, and evaluation measures. Wherever possible, the measurement of progress toward goals should focus on health outcome indicators, rather than on intermediate measures such as process or outputs. A project lacking a complete and well-conceived evaluation protocol as part of the planned activities may not be funded.

### **Public Health System Reporting Requirements**

This program is subject to the Public Health System Reporting Requirements (approved under OMB No. 0937-0195). Under these requirements, the community-based nongovernmental applicant must prepare and submit a Public Health System Impact Statement (PHSIS). The

PHSIS is intended to provide information to State and local health officials to keep them apprised of proposed health services grant applications submitted by community-based nongovernmental organizations within their jurisdictions. The project abstract may be used in lieu of the one-page PHSIS.

Community-based nongovernmental applicants are required to submit the following information to the head of the appropriate State and local health agencies in the area(s) to be impacted no later than the Federal application receipt due date:

1. A copy of the face page of the application (Standard Form (SF) 424).
2. A summary of the project (PHSIS or project abstract), not to exceed one page, which provides:
  - A description of the population to be served.
  - A summary of the services to be provided.
  - A description of the coordination planned with the appropriate State and local health agencies.

## SECTION TWO: Application and Review Process

### 2.A. APPLICATION PROCESS

#### Who Can Apply for Funds

Any public or private entity, including an Indian tribe or tribal organization (as those terms are defined at 25 USC 450b) [42 CFR 51a.3].

#### Funding Preference

Preference will be given to those States, Jurisdictions, or Territories that have received a previous grant under the Genetic Services initiative, “State Development Grants for Newborn Screening Efforts and Infrastructure Development” and/or under the Office of Data and Information Management initiative “Data Utilization and Enhancement.” States, Jurisdictions or Territories that have received a Genetic Services Implementation Grant will not be considered.

MCHB preference is for the State public health agency to be the grantee. A State public health agency may elect to develop an integrated newborn screening service system with a focus on a political subdivision. **Only one application will be considered from each State.**

#### Project Period and Size of Award

The project period for these cooperative agreements starts April 1, 2003. The estimated length of the project period, size of each award and number of awards to be funded are:

Project Period:	4 years
Estimated Size of Each Award:	\$300,000
Estimated Number of Awards:	5

Funding is limited to no more than \$300,000 in Federal funds per year for both direct and indirect costs. The project period is four years. **Indirect costs will be limited to 25 percent of the modified total allowable direct costs or the actual indirect cost rate, whichever is less.**

If the applicant does not have a currently effective indirect cost rate, the indirect costs will be limited to a maximum provisional rate of 10 percent of direct salaries and wages (exclusive of fringe benefits) while a predetermined indirect cost rate is negotiated.

## **Requesting an Application**

- **Information/Paper Copies**

Request information and paper copies of the application guidance and forms by CFDA number (93.110) from:

Grants Management Officer, MCHB  
HRSA Grants Application Center  
901 Russell Avenue  
Suite 450  
Gaithersburg, MD 20879

Telephone: (877) 477-2123  
E-mail: [hrsagac@hrsa.gov](mailto:hrsagac@hrsa.gov)

- **Electronic Access**

Application guidance and forms for MCHB programs are available on the World Wide Web at: <http://mchb.hrsa.gov/grants>.

The Federal Register Notice can be found at:  
[http://www.access.gpo.gov/su\\_docs/aces/aces140.html](http://www.access.gpo.gov/su_docs/aces/aces140.html)

## **Critical Dates**

- The projected **start date** for cooperative agreements funded under this guidance is April 1, 2003.
- A **notice of intent** to submit an application should be submitted to MCHB by September 30, 2002. (See **Attachment “B”**)
- **The application deadline is December 3, 2002.** Applications will be considered as meeting the deadline if they are: (1) received on or before the deadline date, or (2) are postmarked on or before the deadline date and received in time for orderly processing and submission to the Objective Review Committee (ORC).

Applicants should request a legibly dated receipt from a commercial carrier or U.S. Postal Service postmark. Private metered postmarks will not be accepted as proof of timely mailing. Late applications will be returned to the applicant.

## **Mailing Address**

All applications must be mailed or delivered to:

HRSA Grants Application Center  
Attention: Grants Management Officer  
CFDA #93.110  
901 Russell Avenue, Suite 450  
Gaithersburg, MD 20879

**Grant applications sent to any address other than the above are subject to being returned.**

The HRSA Grants Application Center will send out confirmation of the receipt of the application. If the acknowledgment of receipt is not received within 15 days of submitting the application, applicants should contact the HRSA Grants Application Center at (877) 477-2123 or by e-mail at [hrsagac@hrsa.gov](mailto:hrsagac@hrsa.gov) to determine the status of the application.

## **Application Assistance**

Staff at the MCHB Central Office and the Regional Offices (**Appendix “D”**) are available to provide assistance in developing project applications to the extent that time and resources permit. While not permitted to assist in the actual writing of the application, staff can comment on abstracts, outlines and drafts, and can respond to specific questions.

Applicants may obtain additional information regarding business, administrative, or fiscal issues related to the awarding of grants/cooperative agreements under this guidance by contacting either/or:

Jacquelyn E. Whitaker  
Grants Management Specialist  
Maternal and Child Health Bureau, HRSA  
Parklawn Building, Room 18-12  
5600 Fishers Lane  
Rockville, Maryland 20857

Telephone: (301) 443-1440  
E-mail: [jwhitaker@hrsa.gov](mailto:jwhitaker@hrsa.gov)

Marilyn Stewart  
Grants Management Specialist  
Maternal and Child Health Bureau, HRSA  
Parklawn Building, Room 18-12  
5600 Fishers Lane  
Rockville, Maryland 20857

Telephone: (301) 443-1440  
E-mail: [mstewart@hrsa.gov](mailto:mstewart@hrsa.gov)

Questions regarding technical and program issues should be directed to either/or:

Michele Lloyd-Puryear, M.D., Ph.D.  
Branch Chief  
Genetic Services Branch  
Maternal and Child Health Bureau, HRSA  
Parklawn Building, Room 18A-19  
5600 Fishers Lane  
Rockville, Maryland 20857

Telephone: (301) 443-1080  
E-mail: [mpuryear@hrsa.gov](mailto:mpuryear@hrsa.gov)

Michael Kogan, Ph.D.  
Director  
Office of Data Information and Management  
Maternal and Child Health Bureau, HRSA  
Parklawn Building, Room 18-41  
5600 Fishers Lane  
Rockville, Maryland 20857

Telephone: (301) 443-8041  
E-mail: [mkogan@hrsa.gov](mailto:mkogan@hrsa.gov)

### **Number of Copies of Application to be Submitted**

Applicants are required to submit one ink-signed hard copy original of the complete application and two hard copies. Additionally, applicants are required to submit a diskette of the abstract.

### **Technical Assistance Call**

Approximately one week after the deadline for notices of intent, technical assistance calls with interested applicants will be scheduled. For information on the calls, please contact Carrie Diener at (301) 443-1080 or [cdiener@hrsa.gov](mailto:cdiener@hrsa.gov).

## **2.B REVIEW PROCESS**

Grant applications will be reviewed by an ORC composed of a multi-disciplinary panel of Federal and non-Federal persons knowledgeable about and familiar with the related policy and program issues of the joint program initiative listed in this guidance. The ORC's recommendations will be forwarded to the Associate Administrator of the Maternal and Child Health Bureau for final approval.

## **2C. STANDARD RATING CRITERIA**

The code of federal regulations (42 CFR 51a. 5) requires that the review and approval of project grants for maternal and child health take the following standard rating criteria into account. Program review criteria specific to this joint program initiative can be found at **Attachment "A"** (page 24 of this Guidance Document).

The Standard Rating Criteria are:

1. The extent to which the project will contribute to the advancement of Maternal and Child Health and/or improvement to the health of CSHCN.
2. The extent to which the project is responsive to policy concerns applicable to MCH grants

and to program objectives, requirements, priorities and/or review criteria (as expanded and defined) and as published in program announcements or guidance materials.

3. The extent to which the estimated cost to the government of the project is reasonable, considering the anticipated results.
4. The extent to which the project personnel are well qualified by training and/or experience for their roles in the project and the applicant organization has adequate facilities and personnel.
5. The extent to which, insofar as practicable, the proposed activities, if well executed, are capable of attaining project objectives.

## **SECTION THREE: Instructions for Completing the Application**

### **3.A. PREPARING THE APPLICATION: FORMAT AND STYLE**

Reviewers will use only the information presented in your application to evaluate your application. It is essential that the application be responsive to the specific review criteria (**Attachment “A”**), is complete and easy to understand. A clearly written and easy to read application should be the goal of every applicant.

Therefore, MCHB urges all applicants to review the application for the following:

- Correct grammar, spelling, punctuation, and word usage.
- Consistency in style. Refer to a good style manual, such as *The Elements of Style* by Professors William Strunk, Jr. and E. B. White, *Words into Type*, *The Chicago Manual of Style*, or Government Printing Office's *A Manual of Style*.
- Consistency of references (e.g., in this guidance document the Maternal and Child Health Bureau is called the Maternal and Child Health Bureau or MCHB.)

### **3.B. HOW TO ORGANIZE THE APPLICATION**

Order of materials to be submitted (UNBOUND, fastened with a sturdy clip in the upper left corner) The Form PHS 5161-1 (includes the SF 424) is also available online as a FormFlow99 fill-in form at: <http://forms.psc.gov/forms/PHS-5161-1/phs-5161-1.html>

- SF 424 Application for Federal Assistance (Cover Page):
  - Item 10, for the Catalog of Federal Domestic Assistance (CFDA) Number: enter 93.110
  - Item 10, for the Program Title, enter *Genetic Services/Data Capacity Building*
  - Item 13, enter the dates for the complete project period, i.e. four years: April 1, 2003 to March 31, 2007
- Table of contents for entire application with page numbers indicated
- Checklist included with Form PHS 5161-1, Rev. 7/00 (Application Kit)
- SF 424A Budget Information--Non-Construction Programs
- Budget Justification
- Key Personnel Form (See **Attachment “H”**)
- SF 424B, Federal Assurances and Certifications
- Project Abstract (**Attachment “F”**) (include diskette with copy of abstract)
- Project Narrative
- Appendices (should include curriculum vitae or biographical sketches, a sample format can be found in **Attachment “G”**)

### 3.C. HOW TO FORMAT THE APPLICATION

#### **APPLICANTS WHO DO NOT FOLLOW THESE GUIDELINES MAY JEOPARDIZE THE REVIEW OF THEIR APPLICATION.**

##### **Required Parts of Application (Other Than Indicated Federal Forms)**

- **Table of Contents**
- **Project Abstract:** The Project Abstract may not exceed **two pages**. Only single-spaced, one-sided pages are acceptable (See **Attachment “F”**). (Include diskette with copy of abstract.)
- **Project Narrative:** **The project narrative may not exceed 40 pages**, double-spaced and one-sided only. This page limit does not include the Project Abstract (above), the Budget Justification, Appendices, the State’s Genetics Plan, the State’s Health Information Technology Plan, or the Work Plan Matrix (**Attachment “I”**).
- **Narrative Budget Justification:** See “**4.C. BUDGET JUSTIFICATION**”

##### **Style Format of Application**

- **Typeface:** Use any easily readable (serified) typeface, such as Times New Roman, Courier, or New Century Schoolbook.
- **Type Size:** Use at least 10-point; 12-point font is preferable. Type density must be no more than 15 characters per inch. No more than six lines of type must be in a vertical inch of a page. Figures, charts, legends, footnotes, etc., may be smaller or denser than required above, but must be readily legible.
- **Page Numbers:** Beginning with the Table of Contents, consecutive Arabic numerals (beginning with 1) should appear centered at the bottom of **each** page, including pages that are in tabular or chart form. This pagination continues through all parts of the application ending with the last page of the appendices. Required Federal forms should also be paginated as part of the application. They will not count against page limitations. **The State’s Genetics Plan, the State’s Health Information Technology Plan DO NOT have to be paginated.**
- **Margins:** The initial left and all right margins should be 1 inch. The left margin may change when using indentation for subheadings. Top and bottom margins should be 1-1/2 inch each throughout the document.
- **Titles:** All major divisions of the application should begin with capitals, in bold, and be centered, i.e., **Project Abstract, Project Narrative, Appendices, Tables.**
- **Subheadings:** Should begin at left, underlined, with further division then indented and identified by alternating, in consecutive order, Arabic numbers and letters.

## SECTION FOUR: Narrative – Content Requirements

### 4.A. THE ABSTRACT: SUMMARY OVERVIEW OF THE PROPOSED PROJECT

The abstract is a **two page** description of the proposed project utilizing the following outline and providing the information requested in **Attachment “F”**. The applicant must include a 3½" diskette of the **Abstract** with the other hard copy application requirements. The **Abstract** must describe the following:

- **Purpose:** Describe the primary purpose of the project, explaining what the overall project proposes to do.
- **Challenges:** Describe the issues that the project is designed to address and how they relate to the program initiatives in this announcement.
- **Goals and Objectives:** State the major goals and objectives for the entire project.
- **Methodology:** Briefly explain the project plan for achieving the goals and objectives.
- **Evaluation:** Describe the techniques being used to track project activities and to measure the achievement of the project goals and objectives.
- **Experience to Date:** Not to exceed more than five accomplishments
- **Text of Annotation:** Prepare a three to five sentence description of your project that identifies the purpose and challenges addressed, the goals and objectives of the project, the activities to attain these goals, and the materials to be developed.
- **Key Words:** Key words are the terms under which your project will be listed in the subject index of the MCHB Abstract of Active Projects (see **Attachment “C”**). Select the most significant terms that describe your project, including the population served.

If the application is funded, the Project Abstract will be published in MCHB's annual publication entitled “Abstract of Active Projects”. This publication, which includes summaries of all MCHB funded projects, is updated annually and is an important mechanism for dissemination of information about MCHB funded projects. It is widely distributed to MCHB grantees, Title V programs, academic institutions, and governmental agencies. Summaries are also available at: <http://www.ncemch.org/databases/default.html>.

### 4.B. THE NARRATIVE: STATING THE PROPOSAL

The following outline should be adhered to as a guide for the development of the Proposal Narrative. **This instruction supercedes the standard narrative guidance on pages 21-23 of the Form PHS 5161-1.**

- **Purpose of the Project:** Two page summary overview.
- **Description of the Current Service System:** Describe the main public and private players, their functions, collaborative relationships, available resources, etc.
- **Problem Statement:** Describe the population, incidence and prevalence of heritable disorders, demographic distribution of heritable disorders; unmet service needs of the population; extent to

which the current system does and does not meet the standard of providing a *comprehensive and seamless continuum of services for newborns and children with or at risk for heritable disorders and their families* and identify service and information gaps which need to be filled.

- **Goals and Objectives:** Identify the goals and objectives which you propose to deal with in this project and describe how they address issues identified in the problem statement.
- **Methodology:** Describe specific strategies and activities to achieve the stated goals and objectives. Describe who will do what, how, and why? Provide a work plan with specific tasks, when they will be performed, and by whom. This work plan should be keyed to the Work Plan Matrix (**Attachment “I”**).
- **Description of Applicant Organization:** Describe historical background, and relevant experience, resources, skills, and capabilities of the applicant that bear on their ability to complete the project. Describe the proposed organization for the project, e.g., staffing, collaborative relationships, advisory bodies, organization chart.
- **Progress Monitoring and Outcome Evaluation:** Describe methods which will be used to assess the on-going performance of the project’s work plan, and achievement of the project’s goals and objectives; *including measures of project impact on program services and patient health outcomes* where feasible.
- **Needed Resources:** Organize a description of project resource requirements around a detailed budget and budget justification.

#### **4.C. THE NARRATIVE: BUDGET JUSTIFICATION**

This application requires a separate narrative budget justification for each dollar amount listed in Section B, line items a - j, of the SF 424A . This narrative does not count against the page limits of the overall application, but should briefly describe and justify the listed project costs. Each category must be described and related to the stated project activities of the project narrative. For example, under **“Personnel,”** all individuals being compensated for salary and/or fringe under Federal project dollars must be listed and their title and role briefly described, as demonstrated in the project overall narrative. Yearly salaries and fringe should be indicated, with the percentage being funded under this project clearly indicated. Under the category **“Travel,”** costs should be broken down by participant, hotel costs, plane fares, etc.

If the applicant listed items under the **“Other”** category, they should not be items more properly listed in another category, e.g. **“Other Travel”** would be in **“Travel”**.

As part of our efforts to streamline the grant process, a **separate budget is required for each budget year requested**. For example, if the applicant organization requests four years of grant support, four budget pages and justifications are required. **Proposals submitted without a budget and justification for each budget year requested may not be favorably considered for funding.** This provides information needed for the next year’s Summary Progress Report.

States are instructed to include travel funds from the State to the Washington, DC area for two persons for each grant year to attend mandatory grantee technical assistance meetings. All travel

must be related to the administration of the grant, and must be justified in the budget narrative. States should consider budgeting for the support of families to attend national and other meetings at the State level as appropriate.

### **Indirect Costs**

If indirect costs are requested, the applicant must submit a copy of the latest negotiated rate agreement. The indirect cost rate refers to the “Other Sponsored Programs/ Activities” rate and not the research rate. **Indirect costs will be limited to 25 percent of the modified total allowable direct costs, or the actual indirect cost rates, whichever is less.**

If the applicant does not have a currently effective indirect cost rate, the indirect costs will be limited to a maximum provisional rate of 10 percent of direct salaries and wages (exclusive of fringe benefits) while a predetermined indirect cost rate is negotiated.

### **4.D. THE APPENDICES**

Appendices should be brief and supplemental in nature, and are not intended to be a continuation of the project narrative. Items usually listed in the appendices, include the following:

- **Rosters of Boards or Executive Committee Members:** Including identification of consumers or consumer representatives.
- **Copies of Written Agreements:** Descriptions of relationships between the proposed project and affiliated departments, institutions, agencies, or individual providers, family members or consumer advocacy groups and the responsibilities of each participant. Examples of such documentation may include: letters of support, understanding, and memoranda of agreement.
- **Job Descriptions:** Descriptions of responsibilities for all professional and technical positions for which grant support is requested and any positions of significance to the program that will be supported by other sources. At a minimum, list the following for each position:
  - Supervisory and administrative responsibilities of the position and to whom they are directed.
  - Functional duties, responsibilities, and overall relationship of the position within the organizational structure of the project.
  - Minimum qualifications for the position: education, training, and experience needed to perform project tasks.

NOTE: Job Descriptions must not exceed 2 pages in length.

- **Curriculum Vitae:** Include vitae for each incumbent in a position for which a job description is submitted. Each curriculum vita must not exceed 2 pages in length. A biographical sketch included in **Attachment “G”** may be used for this purpose.

## **SECTION FIVE: Attachments to Guidance**

### **5.A. INSTRUCTIONAL ATTACHMENTS**

**Attachment “A”:** *Genetic Services & Data Capacity Building Joint Program Initiative*, program background and the specific goals and purposes of the program initiative included in this Application Guidance for Competing New Proposals.

**Attachment “B”:** *Notice of Intent to Submit an Application.*

**Attachment “C”:** *MCHB Key Words*

**Attachment “D”:** *Regional Office Program Consultants*

**Attachment “E”:** *Regional Genetic Networks*

### **5.B. ATTACHMENTS TO BE SUBMITTED WITH THE APPLICATION:**

**Attachment “F”:** *Abstract.* An abstract must be submitted with the application. Include a diskette with a copy of the abstract. This abstract will be updated yearly as a requirement of the annual Summary Progress Report.

**Attachment “G”:** *Biographical Sketch* sample format (2 pages)

**Attachment “H”:** *Key Personnel*, Supplement to Section F of the SF 424A

**Attachment “I”:** Work Plan Matrix.

# Attachment “A”

## Joint Program Initiative Genetic Services Program Data Capacity Building Program

### PROMOTING INTEGRATION OF STATE HEALTH INFORMATION SYSTEMS AND NEWBORN SCREENING SERVICE SYSTEMS FOR MONITORING AND ENSURING QUALITY SERVICES TO NEWBORNS AND CHILDREN WITH OR AT RISK FOR HERITABLE DISORDERS

#### PURPOSE

Newborn screening programs in the U.S. are a public health activity run by State public health departments to detect genetic and other congenital conditions for which early and timely intervention can eliminate or reduce severe health problems, including death. Screening takes place within a system with the following components: screening, short-term follow-up; diagnosis; management; evaluation, and education for the consumer and public. Partnerships with public health, community-based providers and families are vital in every component of this system. Assuring that results of newborn screens are shared with the child’s ongoing source of comprehensive care, or “medical home,” is a vital part of this system.

The purpose of this grant activity is to assist States in enhancing, expanding and/or improving their public health information infrastructure to integrate their State Genetic Newborn Screening Systems with public and private health care delivery systems to enhance care for newborns and children with or at risk for heritable disorders. While program integration and coordination is the primary goal, data integration will be used as a tool for enhancing program coordination.

The purpose is two-fold:

- To enhance and expand State health information systems to monitor access to care and outcomes related to child health; **AND**
- To enhance, expand and improve State Genetic Newborn Screening Programs (screening, counseling, testing, follow-up and sub-specialty services<sup>1</sup>) and better integrate these programs with the State Title V Community-based System of Services for CSHCN.

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<sup>1</sup> *Journal of Pediatrics*, Volume 137, Number 4, October 2000, Supplement, “U.S. Newborn Screening Systems Guidelines II: Follow-up of Children, Diagnosis, Management, and Evaluation Statement of the Council of Regional Networks for Genetic Services (CORN)”:

MCHB expects that these projects will be developed as an integral component of the State's Title V CSHCN system of care delivery and will show strong active involvement and partnering between the State MCH, CSHCN and Information Technology Directors. They are intended to supplement and/or complement existing activities initiated and funded by States, local communities, and Federal agencies.

### **NEWBORN SCREENING TASK FORCE REPORT**

This grant initiative to integrate State genetic newborn screening programs and relevant information systems will further the implementation of the Newborn Screening Task Force Report<sup>2</sup> recommendations:

- Effective newborn screening systems require an adequate public health infrastructure and must be integrated with the health care delivery system.
- Public health agencies must involve health professionals, families, and the general public in the development, operation, and oversight of newborn screening programs.
- Public health agencies must ensure adequate infrastructure and policies for surveillance and research related to newborn screening.
- Public health agencies should ensure adequate financing mechanisms to support a newborn screening program.

More specifically, the Newborn Screening Task Force Report recommends that grants from HRSA “facilitate and foster the involvement of newborn screening systems in infrastructure development activities in States.” “Such grants should encourage States to consider integration of heelstick programs with a core set of other newborn programs, including birth registration, immunization, newborn hearing screening, and possibly the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) program.” Furthermore, the Task Force recommends, “State public health agencies, working under legislative authority, have the

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- Screening: Testing of newborns
  - Follow-up: Rapid location, follow-up, and referral of the screen-positive infant to medical home and/or sub-specialist, to include a flow diagram for follow-up functions
  - Diagnosis: Evaluation of the infant with a positive screening test to make a definitive diagnosis or exclude the disorder
  - Management: Rapid planning and implementation of long-term therapy
  - Evaluation: Process evaluation of the State public health activities, as well as outcomes evaluation of the newborn screening system overall.

<sup>2</sup>*Pediatrics*, Volume 106, Number 2, August 2000, Supplement, “Serving the Family From Birth to the Medical Home: A Report from the Newborn Screening Task Force Convened in Washington DC, May 10-11, 1999”

ongoing responsibility to ensure quality and evaluate program effort. States and their State public health agencies should:

- Maintain a newborn screening (NBS) system that has appropriate evaluation, performance monitoring, and quality assurance activities from initial screening, through follow-up, diagnosis, treatment, and services through adolescence and adulthood;
- Conduct oversight of program operations, including those outside the public health agency; and
- Monitor and evaluate program performance through collection, assembly, analysis and reporting of data, including outcome evaluations.”

### **PROGRAM INTEGRATION**

These State integrated newborn screening service system cooperative agreements will support States in their development, expansion or improvement of a comprehensive and seamless continuum of services for children with heritable disorders and their families, including: identification, diagnosis, counseling, treatment, enrollment in Medicaid or the State Children's Health Insurance Program (SCHIP) when appropriate, referral to a medical home<sup>3</sup>, access to family support and enabling services, to improve health outcomes. The integration of heelstick programs with a core set of other newborn programs, including birth registration, immunization, newborn hearing screening, and possibly the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) program, vital statistics information and Medicaid data in the proposed systems should be strongly considered.

The States will accomplish effective referral and follow-up through Title V CSHCN systems of care to facilitate, at a minimum, access to medical homes, family to family support, and relevant enabling and direct health care services.

### **DATA INTEGRATION**

Inherent to this process is the development of a child health profile: an on-line electronic system for storing, sharing, using, and evaluating child-health information such as newborn metabolic and hearing screening results. This integrative approach allows: population-based and program specific data to be used by public health programs for such efforts as needs assessments; personal health data access, as necessary, by providers for treatment and the use of public health and other relevant data through data exchange to optimize delivery of care.

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<sup>3</sup>The AAP states that a medical home can be a physician's office, a hospital outpatient clinic, a community health center or school-based clinic, as long as it provides the services that constitute comprehensive care. American Academy of Pediatrics new policy statement (2002) <http://www.aap.org/policy/s060016.html>

Integration of child health information at the point of service delivery is not easy to achieve. While information technology has proliferated and advanced dramatically in the last ten years, the application of information technology to health care and policy formation around health care delivery has not been well coordinated either among public health agencies, or between public and private health sectors. Health information systems in the private sector increasingly are exchanging data with other private sector systems to increase efficiencies and quality of care, but they rarely exchange data with the public health sector, which has population-based information.

The restructuring of the public/private health care delivery system needs to include, as an integral component at the State level, the development, enhancement and on-going support of an integrated newborn screening service system to assure and facilitate education for the consumer and public, appropriate and coordinated sample collection, laboratory testing, follow-up diagnosis, timely treatment, tracking of outcomes and ultimately referral to a medical home. This process will result in a decrease of morbidity, mortality, disability and attendant healthcare costs to the family and individual.

These cooperative agreements will contribute to the formulation of a shared vision of Integrated Newborn Screening Service Systems (INBSSS). Components of such a system include: public/private partnerships; the integration of a wide range of public health and private health care, enabling and direct health care services; the development of an effective information infrastructure; a balance between accountability and consumer demands; the control of costs; the assurance of medical privacy; and the ability to respond to demands for performance measurement.

## **SPECIFIC REQUIREMENTS**

### **Submitted with Application:**

In addition to meeting the General Instructions and Requirements in **SECTIONS ONE, TWO, THREE** and **FOUR** of this guidance, applicants must, as a condition for funding:

1. Provide a copy of both the State's Genetics Plan and the State's Health Information Technology Plan. (DO NOT include in the page count for the Narrative or the Appendices.)
2. Organizational Structure: Briefly describe the State level agencies responsible for providing newborn screening services. Include an organizational chart to illustrate internal collaborative relationships and collaborative relationships with Medicaid, academic institutions, newborn screening and/or genetics advisory committees, community-based health and social service providers, and consumer groups.

Within this structure, identify the entity(ies) responsible for managing/administering newborn screening services, including the department(s), unit(s), staff, and newborn screening/genetics planning/advisory/evaluation bodies.

3. Provide two flow charts:

- Service flow: showing what happens along the continuum of service delivery (screening, counseling, testing, follow-up and sub-specialty services) for families with newborns or children with or at risk for heritable disorders. Include access to medical homes, family-to-family support and other enabling and direct health care services, as relevant. The flow chart should show who refers patients to whom, and who does the necessary follow-up, all the way out the branching tree of the comprehensive and seamless continuum of services.
- Data flow: showing who collects and transfers what data to whom, to *monitor and support* the service delivery system.

4. Complete **Attachment “I”**: Work Plan Matrix. This matrix can be included in either the Narrative or the Appendices of your application. (DO NOT include in the page count for the Narrative or the Appendices.)

**Data Requirements:**

To promote the development of a national network of integrated and interoperable public health systems, recipients of funding under this announcement should ensure that information systems developed or purchased with these funds meet the following data and technical specifications. These specifications are derived from industry standards in the areas of data types, code sets and vocabularies, messages for data exchange, and technology systems standards.

Awardees must comply with Electronic Data Surveillance System<sup>4</sup> (NEDSS) standards and technical requirements including data types, code sets, vocabularies and messages for data exchange technical systems standards. Information technology to support these public health functions should be consistent with the public health information technology (IT) functions and specifications and the NEDSS Architecture (<http://www.cdc.gov/nedss>).

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<sup>4</sup>To better manage and enhance the large number of current surveillance systems and allow the public health community to respond more quickly to public health threats (e.g., outbreaks of emerging infectious diseases, bioterrorism, etc.), CDC is implementing the National Electronic Disease Surveillance System (NEDSS). When completed, NEDSS will electronically integrate and link together a wide variety of surveillance activities and will facilitate more accurate and timely reporting of disease information to CDC and state and local health departments. Consistent with recommendations proffered in the 1995 report, *Integrating Public Health Information and Surveillance Systems*, NEDSS will include data standards, an internet based communications infrastructure built on industry standards, and policy-level agreements on data access, sharing, burden reduction, and protection of confidentiality. [http://www.cdc.gov/od/hissb/act\\_int.htm](http://www.cdc.gov/od/hissb/act_int.htm)

Awardees must demonstrate and specify a strong working relationship with their respective State's NEDSS and CDC Bio-terrorism (BT) named Coordinators. At a minimum and where possible, the awardee should have a working relationship with the local NEDSS and BT regulations and guidances and be included in their local NEDSS and BT committees.

Data types should be consistent with the HL7 Reference Information Model/Public Health Conceptual Data Model. Wherever applicable, they should also be consistent with the Public Health Logical Data Model. Environmental health tracking data not currently covered by the Public Health Logical Data Model will be specified as a supplement to the model in 2002. These specifications will include data types and codes and vocabularies for those data types.

Data exchange between public health partners should use Public Health Notification Message (HL7 Version 3) compatible data messages. Specific messages for environmental health tracking will be developed in this format during 2002.

### **Narrative Content:**

1. The applicant should describe the current overall service system: the degree to which it meets the standard of a comprehensive and seamless continuum of care, to include related information and service gaps (e.g., with reference to health information needs assessment studies and the State's Genetics Plan), and which of those gaps the specific activities in this proposal are intended to fill.
2. The applicant should discuss the feasibility of the retrieval of patient data by the community health care provider (e.g. medical home) at the point of service through standard reports and system queries. The goal is to provide a query system on a "need to know" basis, in compliance with State and/or Federal confidentiality and privacy laws and regulations. The applicant is encouraged to include a discussion of a road map for the incremental development of an integrated overall system of care over the longer term.
3. The applicant should be cognizant of issues of informed consent, confidentiality, access to medical records, and ethical, legal, social, and privacy issues related to grant activities.
4. If the applicant is not the MCHB Title V Program, the applicant must address how they will collaborate with the MCHB Title V Program in the design, implementation, coordination, and evaluation of their integrated newborn screening service system.
5. The applicant should discuss how this project would complement current MCHB Title V Block Grant Performance measurements.
6. The applicant should describe how they will coordinate funding mechanisms and the delivery of services for newborns and children with or at risk for heritable disorders with other related Federal MCH Special Projects of Regional and National Significance (SPRANS) to include existing and planned linkages and joint planning mechanisms. Related SPRANS supported activities may include the Community Integrated Service Systems (CISS) Program and the State Systems Development Initiative (SSDI).

7. The applicant should describe the current status of an advisory body that advises the State on integrated newborn screening service system policy developments. To the extent possible, such an entity should be:
  - Multidisciplinary, to include pediatricians and other primary care health professionals who provide medical homes for children and pediatric subspecialists; have meaningful representation of lay advocates/families, scientists, ethicists, legal representatives, third-party payers, appropriate government agencies, and other concerned citizens.
  - Advisory to State officials about screening for particular conditions based on accepted standards and current knowledge and be consulted about the development of related State regulations.
  - Involved in the review of new tests under consideration by the State and in the development of pilot programs for new tests.
  - Involved in the ongoing evaluation of all aspects of the State's process for newborn screening. Oversight activities should include review of: testing, follow-up, and treatment efforts; the impact on families receiving a false-positive screening results; and the State's process for handling consumer input including grievances.
  
8. The applicant should address the following data integration areas:
  - Where care is fragmented
  - Where data sources are not integrated
  - Where there is agreement among entities to engage in data integration
  - Criteria used for hardware and software development
  - How data will be used
  - Who will use the data
  - How the use of the data will benefit newborns and children with or at risk for heritable disorders
  - Who has access to the data (and what parts of it), and for what purposes
  - Capacity of data systems
  - Anticipated results of funded projects in terms of data and program outcomes, data components, interagency collaborations, and staff accountable for the effort.

## **RESOURCES**

1. National Newborn Screening & Genetics Resource Center (NNSGRC) at: <http://genes-r-us.uthscsa.edu/> provides information and resources in the area of newborn screening and genetics to benefit health professionals, the public health community, consumers and government officials. The following information is available from the NNSGRC:
  - The *Guidelines for Clinical Genetics Services for the Public's Health* developed by the Council of Regional Networks for Genetic Services (CORN)

- Meeting proceedings and background information from the November 1999 technical assistance meeting of State Planning Grantees, *“Incorporating Genetic Medicine & Technology Into Practice and Service”*
  - Meeting proceedings and background information from the September 2000 technical assistance meeting of State Planning Grantees, *“Integration of Science and Technology into Public Health”*
  - Meeting proceedings and background information from the March 2002 technical assistance meeting of State Planning Grantees, *“Summary of Meeting: State Development Grants for Newborn Screening and Infrastructure Development”*
  - Kaye CI, Laxova R, Livingston JE, Lloyd-Puryear MA, Mann M, McCabe ERB, Therrell BL, *Community Genetics: Integrating Genetic Services into Public Health—Guidance for State and Territorial Programs from the NNSGRC* (Community Genet 2001;4:175-196)
2. *Serving the Family From Birth to the Medical Home: A Report from the Newborn Screening Task Force Convened in Washington DC, May 10-11, 1999*, Pediatrics, Volume 106, Number 2, August 2000, Supplement is available upon request from the HRSA Information Center by phone: Toll-Free Number: 888-Ask HRSA or on-line, at: <http://www.ask.hrsa.gov/Instructions.cfm> The Inventory Code Number is: MCHM065.
  3. Rhode Island Department of Health Genetics website at: <http://www.health.state.ri.us/genetics/genetics.htm>
  4. *Title V Information System (Title V IS)* electronically captures data from annual Title V Block Grant applications and reports submitted by all 59 U.S. States, Territories, and Jurisdictions and provides information on key measures of maternal and child health in the United States, at: <http://www.mchdata.net/>
  5. The Centers for Medicare & Medicaid Services (CMS) (formerly HCFA), HRSA and CDC have joined together to launch a coordinated strategy aimed at reducing barriers to sharing data between Medicaid and health agencies and supporting innovative approaches to the design and implementation of State information systems that foster collaboration among these programs. This letter from the Administrators of HCFA, HRSA and CDC to State Health Officers and State Medicaid Directors provides information on the first set of activities conducted to support collaborations for data sharing between State Medicaid and health agencies. Available at: <http://cms.hhs.gov/states/letters/smd10228.asp>
  6. *Integrated Health Information Systems Investment Analysis Guide*, Centers for Disease Control and Prevention/Health Resources and Services Administration -- Implementation Version - April 1, 1998. Available at: <http://www.hrsa.gov/investment.htm>. HIPAA and NEDSS standards and technical requirements including data types, code sets, vocabularies and messages for data exchange technical systems standards are available at: [www.cdc.gov/nedss](http://www.cdc.gov/nedss)

7. Title XXVI of the Children's Health Care Act of 2000, "Screening for Heritable Disorders," establishes a program to improve the ability of States to provide newborn and child screening for heritable disorders. Title XXVI enacts three sections of the Public Health Service (PHS) Act: Sections 1109, 1110, and 1111. (42 USC 6A IX Part A Sec. 300b-8. Improved newborn and child screening for heritable disorders <http://www4.law.cornell.edu/uscode/42/300b-8.html>) If you cannot access this URL, to request a copy, please call: 301-443-1080.

## **REVIEW CRITERIA**

1. The extent to which the project will contribute to the advancement of Maternal and Child Health and/or improvement to the health of CSHCN.

### Description of Current Status: (10 points)

- Did the applicant describe the **current status** of the State's *overall service system* of care for CSHCN with respect to:
  - Their newborn metabolic screening program, to include data system and services, follow-up, diagnosis, management, program evaluation and reporting requirements?
  - The information and service links which facilitate referral from the newborn metabolic screening program to medical homes, family-to-family support and programs for early treatment and management?
  - The integration of information and service systems for the newborn metabolic screening program with the administration of the Maternal and Child Health Services Block Grant (Title V), including CSHCN and other related programs?
  - The State's newborn screening and/or genetics advisory body?

### Description of Proposed Activities: (25 points)

- Did the applicant describe the State's proposed activities to be accomplished with this grant with respect to:
  - The needs identified in the State's genetics plan as they relate to the integration of the State's information system(s) and service programs around newborn heelstick/metabolic screening? Specifically, did the applicant address the following data integration areas:
    - ⇒ Where care is fragmented
    - ⇒ Where data sources are not integrated
    - ⇒ Where there is agreement among entities to engage in data integration
    - ⇒ Criteria used for hardware and software development
    - ⇒ How data will be used

- ⇒ Who will use the data
  - ⇒ How use of the data will benefit newborns and children with or at risk for heritable disorders
  - ⇒ Who has access to the data (and what parts of it), and for what purposes
  - ⇒ The capacity of data systems
  - ⇒ Anticipated results of funded projects in terms of data and program outcomes, data components, interagency collaborations, and staff accountable for the effort.
- Did the applicant address the development of effective information, service referral and follow-up through the State's *overall service system* of care for CSHCN by ensuring to the extent possible:
    - The integration of State information systems?
    - Access to medical homes?
    - Access to providers for early treatment and management?
    - Access to programs for early treatment and management?
    - Family-to-family support?
    - Routine reporting requirements?
    - The integration of child related public health agency data such as immunization registries, vital records, newborn hearing screening, birth defects, chronic disease, early identification, WIC, Medicaid, and other related programs in the respective State?
    - Incentives for assessing and maintaining data quality?
    - That the newborn screening and/or genetics advisory body is multidisciplinary, advises State officials, involved in the review of new tests and the ongoing evaluation of all aspects of the State's process for newborn screening to include oversight activities?
  - Does this grant proposal contribute to system capacity to assure a seamless and comprehensive continuum of services to newborns and children with or at risk for heritable disorders, with an emphasis on tracking and follow-up, referral to family to family support and the establishment of a medical home?
  - If funded, will this grant be an integral component of the State's CSHCN systems of care? The State's Title V supported MCH Programs? The State's information technology integration efforts? The State's BT and NEDSS initiatives?
  - Did the applicant show strong involvement of the State Title V, CSHCN and Health Information Technology Directors in the project?
  - Did the applicant provide evidence of partnerships/linkages such as written agreements, shared staffing arrangements, interagency meetings, impersonal connections such as computer networks or centralized resource databases, or activities that take place outside

an agency such as a coordinator based on-site at another agency or cross training of staff with or in other agencies?

- Did the applicant discuss the feasibility of the retrieval of patient data by the health care provider at the point of service through standard reports and system queries?
  - Did the applicant address the ease of access of relevant data particularly for the provider of services? Time delays and burdens in loading and making available data? User support for data access and use? Report and display flexibility to meet individual needs?
  - Did the applicant address confidentiality issues for both clients and stakeholders?
  - Did the applicant address Web access?
  - Did the applicant address sustainability of the project upon completion of these awards?
2. The extent to which the project is responsible to policy concerns applicable to MCH grants and to program objectives, requirements, priorities and/or review criteria (as expanded and defined) and as published in program announcements or guidance materials. (10 points)
- Did the applicant describe how the project will:
    - Further the agenda for *Healthy People 2010*?
    - Place emphasis on improving service delivery to women, children, youth and families from communities with limited access to comprehensive care?
    - Involve individuals from the populations to be served in the planning and implementation of the project?
    - Develop, support and further effective partnerships with both nongovernmental (such as medical homes), governmental entities and stakeholders (to include families)?
    - Complement current MCHB Title V Block Grant Performance measurements?
  - Is the applicant cognizant of issues of informed consent, confidentiality, access to medical records, and ethical, legal, social, and privacy issues related to grant activities?
3. The extent to which the estimated cost to the government of the project is reasonable, considering the anticipated results. (10 points)
4. The extent to which the project personnel are well qualified by training and/or experience for their roles in the project and the applicant organization has adequate facilities and personnel. (10 points)

5. The extent to which, insofar as practicable, the proposed activities, if well executed, are capable of attaining project objectives. (25 points)
- Did the applicant complete the Work Plan Matrix (Attachment “I”)?
  - Did the applicant describe the activities they will use to achieve each project goal and objective?
  - Are the project goals/objectives responsive to the program initiative in this announcement and the needs of the targeted population(s)?
  - Do the goals realistically reflect the link between the stated issues, the intent and purpose of the program or service, and the level (State or local) at which the program or services are to be implemented?
  - Are the objectives **S-M-A-R-T**<sup>5</sup>?
    - **Specific:** Linked to clear tasks and outcomes, Title V Performance Measures
    - **Measurable:** Process–monitoring, outcome–evaluation
    - **Attainable:** Given socio-cultural, political and technical reality and capacity of State/local system
    - **Relevant:** Current and planned programs and services
    - **Time-Bound:** Tasks to be accomplished within well thought out timeframes
6. The strength of the project’s plans for evaluation. (10 points)
- Did the applicant incorporate a carefully designed and well-planned evaluation protocol capable of demonstrating and documenting measurable progress toward achieving the project's stated goals?
  - Has the applicant developed a systematic plan for:
    - Monitoring and assessing successful completion of program tasks?
    - Assessing resultant improvements in the service system?
    - Achieving improved outcomes for the target population?

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<sup>5</sup> Based on the work of Joseph Telfair, DrPH, MSW/MPH, Associate Professor, University of Alabama at Birmingham

## **Attachment “B”**

### **Notice of Intent to Submit an Application**

#### **Intent to Apply for CFDA #93.110:**

If you intend to submit an application for funding under this FY 2003 joint program initiative, please notify MCHB by **September 30, 2002**.

You may notify MCHB of your intent to submit an application in writing, three ways:

Electronic Mail: [cdiener@hrsa.gov](mailto:cdiener@hrsa.gov)

Mail: Attn: Carrie Diener  
GSB/MCHB  
Room 18A-19  
5600 Fishers Lane  
Rockville, Maryland 20857

FAX: (301) 443-8604

Your “notice of intent to submit an application” will be used as a mechanism to deliver technical assistance. We appreciate your attention to this notice and thank you for your support.

Michele Lloyd-Puryear, M.D., Ph.D.  
Chief  
Genetic Services Branch

Michael Kogan, Ph.D.  
Director  
Office of Data Information and Management

# Attachment “C”

## Keywords for Projects Funded by the U.S. Maternal and Child Health Bureau (MCHB)

A list of keywords used to describe MCHB-funded projects follows. Please choose from this list when selecting terms to classify your project.

Please note that this list is constantly under development: new terms are being added and some terms are being deleted. Also, this list is currently being revised so that it will match more closely the approved list of keywords in the MCH Thesaurus. In the meantime, however, this list can be used to help select keywords to describe MCHB-funded projects.

If no term on this list adequately describes a concept which you would like to convey, please select a term which you think is appropriate and include it in your list of keywords.

---

2010 Express	Anemia	Breastfeeding
Abstinence	Anticipatory Guidance	Bronchopulmonary Dysplasia
Abstinence Education	Appalachians	Bullying
Abstinence-Only Education	Arthritis	Burns
Access to Health Care	Asian Language Materials	Cambodians
Adolescent Health Programs	Asians	Capitation
Adolescent Nutrition	Asthma	Care Coordination
Adolescent Parents	Attachment	Caregivers
Adolescent Pregnancy	Attachment Behavior	Case Management
Adolescent Pregnancy Prevention	Attention Deficit Disorder	Cerebral Palsy
Adolescent Risk Behavior	Audiology	Character Development
Prevention	Audiometry	Chelation Therapy
Adolescents	Audiovisual Materials	Child Abuse
Adolescent Transition	Automated Auditory Brainstem	Child Abuse Prevention
Adolescents with Disabilities	Response	Child Care
Advocacy	Baby Bottle Tooth Decay	Child Care Centers
African Americans	Battered Women	Child Care Health Consultants
African American Families and	Behavior Disorders	Child Care Workers
Children	Behavioral Pediatrics	Child Morbidity
Agricultural Safety	Benefit Package	Child Mortality
AIDS	Bereavement	Child Neglect
AIDS Prevention	Bicycle Helmets	Child Nutrition
Alaska Natives	Bicycle Safety	Child Sexual Abuse
Alcohol	Bilingual Services	Childhood Cancer
American Academy of Pediatrics	Biochemical Genetics	Children with Special Health Care
American Association of Health	Blindness	Needs
Plans	Blood Pressure Determination	Child Death Review
American College of Obstetricians	Body Composition	Chronic Illnesses and Disabilities
and Gynecologists	Bonding	Cleft Lip
American Public Health Association	Brain Injuries	Cleft Palate
Amniocentesis	Breast Pumps	Clinical Genetics

Clinical Risk Groups	Disabilities	Family Support Services
Clinics	Depression	Family to Family Health
Coalition Building	Developmental Disabilities	Information Centers
Cocaine	Developmental Evaluation	Family Violence Prevention
Cochlear Implant	Developmental Screening	Farm Workers
Collaboration	Diagnosis	Fathers
Collaborative Office Rounds	Diarrhea	Feeding Disorders
Communicable Diseases	Dietitians	Fetal and Infant Mortality Review
Communication Disorders	Dispute Resolution	Fetal Alcohol Effects
Communication Systems	Dissemination	Fetal Alcohol Syndrome
Community	Distance Education	Financing
Community Based Health	Divorce	Food Preparation in Child Care
Education	DNA Analysis	Formula
Community Based Health Services	Down Syndrome	Foster Care
Community Based Preventive	Drowning	Foster Children
Health	Early Childhood Caries	Foster Homes
Community Development	Early Childhood Development	Foster Parents
Community Health Centers	Early Childhood Education	Fragile X Syndrome
Community Integrated Service	Early Childhood and Family	Genetic Counseling
System	Environment	Genetic Disorders
Community Participation	Early Intervention	Genetic Screening
Community Partnerships	Electronic Bulletin Boards	Genetic Services
Community Systems Integration	Electronic Mail	Genetics Education
Compliance	Eligibility Determination	Gestational Weight Gain
Comprehensive Primary Care	Emergency Medical Services for	Glucose Intolerance
Computer Linkage	Children	Governors
Computer Systems	Emergency Medical Technicians	Grief
Computers	Emergency Room Personnel	Gynecologists
Conferences	Emotional Disorders	Hawaiians
Congenital Abnormalities	Emotional Health	Head Start
Congenital Hearing Loss	Employee Assistance Programs	Health Care Coverage
Congenital Hypothyroidism	Employers	Health Care Financing
Consortia	Employment of Parent	Health Care Reform
Continuing Education	Enabling Services	Health care utilization
Continuity of Care	Enteral Nutrition	Health Education
Cost Effectiveness	EPSDT	Health Insurance
Counseling	Erythrocyte Protoporphyrin	Health Insurance Enrollment in
County Health Agencies	Ethics	Child Care
Cranio-facial Conditions	Evoked Otoacoustic Emissions	Health Maintenance Organizations
Cross System Strategies	Failure to Thrive	HP 2010 for CSHCN
CSHCN Screener	Families	HP 2010 for CSHCN State
Cultural and Linguistic Competence	Family Centered Health Care	Implementation
Cultural Diversity	Family Centered Health Education	Health Professionals
Cultural Competence	Family Characteristics	Health Promotion
Cultural Sensitivity	Family Environment	Health Supervision
Curricula	Family Financial Security and	Healthy Communities
Cystic Fibrosis	Socio-Emotional Development of	Healthy Mothers Healthy Babies
Cytogenetics	Children	Coalition
Data Analysis	Family Focus Groups	Healthy People 2010
Data Collection	Family Medicine	Healthy Start Initiative
Data Systems	Family Participation	Healthy Tomorrows Partnership for
Databases	Family Planning	Children
Deafness	Family Professional	Hearing Disorders
Decision Making Skills	Collaboration/Partnerships	Hearing Loss
Delayed Development	Family Relations	Hearing Screening
Dental Sealants	Family Support Case Management	Hearing Tests
Dental Treatment of Children with	Family Support Programs	Hemoglobinopathies

Hemophilia	Lead Poisoning Prevention	Network Development
Hepatitis B	Lead Poisoning Screening	Networking
Hispanics	Leadership Development	Neurological Disorders
Hispanic Access to Health Care	Leadership Training	New Freedom Initiative
Hispanic Families and Children	Learning Disabilities	Newborn Screening
HIV	Legal Issues	Newborn Screening Education
Hmong	Life Support Care	Nurse Midwives
Home Health Services	Literacy	Nurses
Home Visiting for At Risk Families	Local Health Agencies	Nutrition
Home Visiting Programs	Local MCH Programs	Obstetricians
Home Visiting Services	Low Birthweight	Occupational Therapy
Homeless Persons	Low Income Population	One Stop Shopping
Hospitals	Lower Birthweight	Online Databases
Hygiene	Males	Online Systems
Hyperactivity	Managed Care	Oral Health
Hypertension	Managed Care Organization	Organic Acidemia
Identification	Managed Competition	Organization and Delivery of Health Services
Illnesses in Child Care	Marijuana	Organizational Self Assessment
Immigrants	Marital Conflict	Otitis Media
Immunization	Maternal and Child Health Bureau	Out-of-Wedlock Sexual Activity
Incarcerated Women	Maternal Nutrition	Outreach
Incarcerated Youth	MCH Research	P. L. 99-457
Individual Education Plan (IEP)	Media Campaigns	Pacific Islanders
Indian Health Service	Medicaid	Pain
Indigence	Medicaid Managed Care	Paraprofessional Education
Individualized Family Service Plans	Medical Genetics	Parent and Professional Collaboration
Infant Health Care	Medical History	Parent Education
Infant Morbidity	Medical Home	Parent Education Programs
Infant Mortality	Medical Necessity	Parent Networks
Infant Mortality Review Programs	Mental Health	Parent Professional Communication
Infant Nutrition	Mental Health Services	Parent Support Groups
Infant Screening	Mental Retardation	Parent Support Services
Infant Temperament	Metabolic Disorders	Parental Stressors
Infants	Mexicans	Parental Visits
Information Networks	Micronesians	Parenteral Nutrition
Information Services	Migrant Health Centers	Parenting Skills
Information Sources	Migrants	Parents
Information Systems	Minority Families	Partnerships
Information System Integration	Minority Groups	Patient Education
Injuries	Minority Health Professionals	Patient Education Materials
Injury Prevention	Mobile Health Units	Pediatric Advanced Life Support Programs
Intensive Care	Molecular Genetics	Pediatric Dentistry
Interagency Cooperation	Morbidity	Pediatric Intensive Care Units
Interdisciplinary Collaboration	Mortality	Pediatric Nurse Practitioners
Interdisciplinary Strategies	Motor Vehicle Crashes	Pediatricians
Interdisciplinary Teams	Multiple Births	Peer Counseling
Internship and Residency	Myelodysplasia	Peer Support Programs
Intubation	National CSHCN Survey	Perinatal Health
Iron Deficiency Anemia	National Information Resource Centers	Periodontal
Iron Supplements	National Programs	Periodontal Disease
Juvenile Rheumatoid Arthritis	Native Americans	Phenylketonuria
Laboratories	Needs Assessment	Physical Disabilities
Lactose Intolerance	Neonatal Intensive Care	Physical Therapy
Language Barriers	Neonatal Intensive Care Units	Pneumococcal Infections
Language Disorders	Neonatal Mortality	
Laotians	Neonates	
Lead Poisoning		

Poisons	Work	Shaken Infant Syndrome
Poison Control Center	Professional Education in Violence	Siblings
Policy Initiatives	Prevention	Sickle Cell Disease
Positive Youth Development	Program Integration	Sleep Disorders
Preconception Care	Provider Participation	Smoking During Pregnancy
Pregnant Adolescents	Psychological Evaluation	Social Marketing
Pregnant Women	Psychological Problems	Social Skills Instruction
Prematurity	Psychosocial Services	Social Work
Prenatal Care	Public Awareness Campaign	Socio-Emotional Development and
Prenatal Diagnosis	Public Health Academic Programs	Maternal and Child Health Services
Prenatal Screening	Public Health Education	Delivery
Preschool Children	Public Health Nurses	Socio-Emotional Development
Preterm Birth	Public Policy	Assessment
Preventive Health Care	Public Private Partnership	Socio-Emotional Development and
Preventive Health Care Education	Puerto Ricans	Medical Home
Primary Care	Pulmonary Disease	Southeast Asians
Primary Care Providers	Quality Assurance	Spanish Language Materials
Professional Education in	Recombinant DNA Technology	Special Education Programs
Adolescent Health	Referrals	Specialized Care
Professional Education in	Regional Programs	Specialized Child Care Services
Behavioral Pediatrics	Regionalized Care	Speech Disorders
Professional Education in	Regulatory Disorders	Speech Pathology
Breastfeeding	Rehabilitation	Spina Bifida
Professional Education in Chronic	Reimbursement	Spouse Abuse
Illnesses and Disabilities	Repeat pregnancy prevention	Standards of Care
Professional Education in	Research	State Health Agencies
Communication Disorders	Residential Care	State Health Insurance Programs (S-
Professional Education in CSHN	Respiratory Illnesses	CHIP)
Professional Education in Cultural	Retinitis Pigmentosa	State Health Officials
Sensitivity	Rheumatic Diseases	State Legislation
Professional Education in Dentistry	Risk Adjustment	State Programs
Professional Education in	Risk Reduction	State Staff Development
Developmental Disabilities	RNA Analysis	State Systems Development
Professional Education in EMSC	Robert Wood Johnson Foundation	Initiative
Professional Education in Family	Runaways	Stress
Medicine	Rural Population	Substance Abuse
Professional Education in Genetics	Safety in Child Care	Substance Abuse Prevention
Professional Education in Lead	Safety Seats	Substance Abuse Treatment
Poisoning	Sanitation in Child Care	Substance Abusing Mothers
Professional Education in MCH	School Age Children	Substance Abusing Pregnant
Professional Education in Metabolic	School-Based Health Centers	Women
Disorders	School Dropouts	Substance Exposed Children
Professional Education in Nurse	School Health Programs	Substance Exposed Infants
Midwifery	School Health Services	Sudden Infant Death Syndrome
Professional Education in Nursing	School Nurses	Suicide
Professional Education in Nutrition	School Mental Health Services	Supplemental Security Income
Professional Education in	School Safety	Program
Occupational Therapy	Schools	Support Groups
Professional Education in Physical	Screening	Surveys
Therapy	Seat Belts	Systems of Care
Professional Education in Primary	Self Esteem	Tay Sachs Disease
Care	Sensory Impairments	Technical Assistance for CSHCN
Professional Education in	Service Coordination	Technology Dependence
Psychological Evaluation	Sex Roles	Teleconferences
Professional Education in	Sexual Behavior	Telemedicine
Pulmonary Disease	Sexuality Education	Television
Professional Education in Social	Sexually Transmitted Diseases	Teratogens

Terminally Ill Children  
Tertiary Care Centers  
Thalassemias  
Third Party Payers  
Title V Programs  
Toddlers  
Training  
Transportation  
Trauma  
Traumatic Brain Injury  
Tuberculosis  
Twins  
Underinsurance  
Underserved

Uninsured  
Unintentional Injuries  
University Affiliated Programs  
Urban Population  
Urinary Tract Infections  
Usher Syndrome  
Vietnamese  
Violence  
Violence Prevention  
Vision Screening  
Vocational Training  
Von Willebrand Disease  
Waiver 1115  
Welfare Reform and Child

Development  
Welfare to Work  
Well Baby Care  
Well Child Care  
WIC  
Women with Congenital Bleeding  
Disorders  
Wraparound Services  
Youth Development Assets  
Youth Risk Behaviors  
Youth in Transition  
Youth with Special Health Care  
Needs

# Attachment “D”

## REGIONAL FIELD OFFICE PROGRAM CONSULTANTS for MCHB

These are the people to contact concerning Maternal and Child Health Bureau Programs within the 10 Department of Health and Human Service's Regional Offices:

### Region I (CT, ME, MA, NH, RI, VT)

Barbara Tausey, M.D., M.H.A.  
Room 1826  
John F. Kennedy Federal Building  
Boston, MA 02203  
(617) 565-1433  
(617) 565-3044 (FAX)  
BTAUSEY@HRSA.GOV

### Region II (NJ, NY, PR, VI)

Shirley Smith, R.N., M.S.  
26 Federal Plaza  
Federal Building, Room 3337  
New York, N.Y. 10278  
(212) 264-2571  
(212) 264-2673 (FAX)  
SSMITH@HRSA.GOV

### Region III (DE, DC, MD, PA, VA, WV)

Frank Herron, P.O.C.  
Public Ledger Building  
150 S. Independence Mall West  
Suite 1172  
Philadelphia, PA 19106-3499  
(215) 861-4379  
(215) 861-4338 (FAX)  
VALOS@HRSA.GOV

### Region IV (AL, FL, GA, KY, MS, NC, SC, TN)

Ketty Gonzalez, M.D., M.P.H. (Acting)  
HRSA Field Coordinator, Southeast Cluster  
Atlanta Federal Center  
61 Forsyth Street, S.W., Suite 3M60  
Atlanta, GA 30303-8909  
(404) 562-7980  
(404) 562-7974 (FAX)  
KGONZALEZ@HRSA.GOV

### Region V (IL, IN, MI, MN, OH, WI)

Dorretta Evans Parker, M.S.W. (Acting)  
233 North Michigan Ave., Suite 200  
Chicago, IL 60601-5519  
(312) 353-4042  
(312) 886-3770 (FAX)  
DPARKER@HRSA.GOV

### Region VI (AR, LA, NM, OK, TX)

Thomas Wells, M.D. M.P.H. (Acting)  
1301 Young Street  
10th Floor, HRSA-4  
Dallas, TX 75202  
(214) 767-3003  
(214) 767-3038 (FAX)  
TWELLS@HRSA.GOV

### Region VII (IA, KS, MO, NE)

Elvira Jarka, P.O.C.  
Federal Building, Room 1728  
601 E. 12th Street  
Kansas City, MO 64106-2808  
(816) 426-5291 ext. 257  
(816) 426-3633 (FAX)  
BAPPELBAUM@HRSA.GOV

### Region VIII (CO, MT, ND, SD, UT, WY)

Joyce DeVaney, R.N., M.P.H.  
Federal Office Building, Room 1189  
1961 Stout Street  
Denver, CO 80294  
(303) 844-3204 ext.215  
(303) 844-0002 (FAX)  
JDEVANEY@HRSA.GOV

### Region IX (AZ, CA, HI, NV, AS, FM, GU, MH, MP, PW)

Reginald Louie, D.D.S., M.P.H.  
Federal Office Building, Room 317  
50 United Nations Plaza  
San Francisco, CA 94102  
(415) 437-8101  
(415) 437-8105 (FAX)  
RLOUIE@HRSA.GOV

### Region X (AK, ID, OR, WA)

Margaret West, Ph.D., M.S.W. (Acting)  
Mail Stop RX-27  
2201 Sixth Avenue, Room 700  
Seattle, WA 98121  
(206) 615-2518  
(206) 615-2500 (FAX)  
MWEST@HRSA.GOV

08/01/2002

# Attachment “E”

## Regional Genetic Networks

### **NEW ENGLAND REGIONAL GENETICS GROUP (NERGG)(CT, ME, MA, NH, RI, VT)**

Fay H. Larson, RN, MS, Nurse Consultant  
State of Connecticut  
Department of Public Health  
Genetics Newborn Screening Program  
410 Capitol Avenue, MS #11 MAT  
PO Box 340308  
Hartford, CT 06134-0308  
Telephone 860-509-8081  
Fax 860-509-7720  
[fay.larson@po.state.ct.us](mailto:fay.larson@po.state.ct.us)  
<http://www.acadia.net/nergg/index.html>

### **THE GENETIC NETWORK OF NEW YORK, PUERTO RICO AND THE VIRGIN ISLANDS (GENES) (NY, PR, VI)**

Kenneth A. Pass, Ph.D.  
Wadsworth Center  
New York State Department of Health  
P.O. Box 509  
Albany, NY 12201-0509  
(518) 473-1993 (voice)  
(518) 486-2095 (fax)  
[kap03@health.state.ny.us](mailto:kap03@health.state.ny.us)  
<http://www.wadsworth.org/index.htm>

### **MID-ATLANTIC REGIONAL HUMAN GENETICS NETWORK (MARHGN)**

**(DE, DC, MD, NJ, PA, VA, WV)**  
Marion Schwartz, R.N., M.S.N.  
New Jersey Department of Health  
120 S. Stockton Street  
P.O. Box 367  
Trenton, NJ 08625  
(609) 633-8981 (voice)  
(609) 633-9060 (fax)  
[Marion.Schwartz@doh.state.nj.us](mailto:Marion.Schwartz@doh.state.nj.us)  
<http://www.pitt.edu/~marhgn/>

### **SOUTHEASTERN REGIONAL GENETICS GROUP (SERGG)**

**(AL, GA, FL, KY, LA, MS, NC, SC, TN)**  
Charles Myers, M.S.W.  
Louisiana Department of Health and Hospitals  
Genetic Diseases Program, Room 308  
P.O. Box 60630  
New Orleans, LA 70160-0630  
(504) 568-5070 (voice)  
(504) 568-7722 (fax)  
[Charlie@dhh.state.la.us](mailto:Charlie@dhh.state.la.us)  
<http://www.emory.edu/PEDIATRICS/sergg/>

### **GREAT LAKES REGIONAL GENETICS GROUP (GlaRGG)**

**(IL, IN, MI, MN, OH, WI)**  
Gary Hoffman, Supervisor  
Newborn Screening Laboratory  
Wisconsin State Laboratory of Hygiene  
465 Henry Mall  
Madison, WI 53706-1578  
(608) 262-4692 (voice)  
(608) 262-5494 (fax)  
[hoffman@mail.slh.wisc.edu](mailto:hoffman@mail.slh.wisc.edu)  
<http://www.waisman.wisc.edu/glargg/index.htmlx>

### **GREAT PLAINS GENETIC SERVICES NETWORK (GPGSN) – Dissolved**

Contact:  
Aurita Prince-Caldwell, M.Ed.  
President, Great Plains Clinical Genetics Society  
Missouri Department of Health  
Jefferson City, MO  
(314) 877-2869  
[PrincA@mail.health.state.mo.us](mailto:PrincA@mail.health.state.mo.us)

### **TEXAS GENETICS NETWORK (TEXGENE) - Dissolved**

Contact for activities related to State genetics planning:  
Peggy Visio, M.S., R.D./L.D.  
University of TX Health Science Center  
at San Antonio  
Department of Pediatrics  
Genetics and Metabolic Disorder Division  
7703 Floyd Curl Drive  
San Antonio, TX 78229-3900  
(210) 567-7479 (fax)  
(210) 567-7465 (voice)  
[visio@uthscsa.edu](mailto:visio@uthscsa.edu)  
<http://www.tdh.texas.gov/texgene/texgene.htm>

**MOUNTAIN STATES GENETIC NETWORK**

**(AZ, CO, MT, NM, UT, NY)**

Joyce Hooker

8129 W. Freemont Avenue

Littleton, CO 80128

(303) 978-0125 (phone and fax)

[msgf@netscape.net](mailto:msgf@netscape.net)

<http://www.mostgene.org>

**PACIFIC NORTHWEST REGIONAL GENETICS**

**GROUP (PacNoRGG)**

**(CA, HI, NV)**

Judith Tuerck, R.N.

Education Coordinator

Pacific Northwest Regional Screening Program

Oregon Health Science University

Crippled Children's Division

P.O. Box 574

Portland, OR 97201

(503) 494-7859 (voice)

(503) 494-2781 (fax)

[tuercki@ohsu.edu](mailto:tuercki@ohsu.edu)

<http://mchneighborhood.ichp.edu/pacnorgg>

**PACIFIC SOUTHWEST REGIONAL GENETICS**

**NETWORK (PSRGN) (AL, ID, OR, WA)**

Fred Lorey, Ph.D.

Clinical Chemistry Laboratory

California Department of Health Services

2151 Berkeley Way, Annex 4

Berkeley, CA 94704

(510) 540-2941 (voice)

(510) 540-3387 (fax)

[florey@dhs.ca.gov](mailto:florey@dhs.ca.gov)

7/25/02 - CDiener

# Attachment “F”

## GENETIC SERVICES PROGRAM DATA CAPACITY BUILDING PROGRAM Joint Initiative

### Abstract

Project Title \_\_\_\_\_  
Principal Investigator/Program Director \_\_\_\_\_  
Organization \_\_\_\_\_  
Address \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
Contact Person \_\_\_\_\_  
Phone ( ) \_\_\_\_\_  
Fax ( ) \_\_\_\_\_ E-mail/World Wide Web Address: \_\_\_\_\_  
Project Period: 4 Years From: 4/1/2003 to 3/31/2007

### NARRATIVE

**Purpose**

**Challenges**

**Goals and Objectives**

**Methodology**

**Evaluation**

**Experience to Date**

**Text of Annotation**

**Key Words**

# Attachment “G”

## Biographical Sketch

Give the following information for all professional personnel contributing to the project beginning with the Project Director. (DO NOT EXCEED 2 PAGES ON ANY INDIVIDUAL)

<b>Name</b> (Last, First, MI)	<b>Title</b>	<b>Birth Date</b> (Month/ Day/ Year)
<b>Education</b> (Begin with baccalaureate or other initial professional education and include postdoctoral training)		
<b>Institution and Location</b>	<b>Degree</b>	<b>Year Completed</b>
<b>Field of Study</b>		
<b>Honors</b>		
<b>Research and Professional Experience</b> (List in reverse chronological order previous employment and experience. List in reverse chronological order most representative publications)		

# Attachment "H"

## Key Personnel

### SUPPLEMENT TO SECTION F of SF 424A

NAME AND POSITION/ TITLE	ANNUAL SALARY	NUMBER OF MONTHS FOR BUDGET	PERCENTAGE TIME	TOTAL FUNDS REQUESTED
	(1)	(2)	(3)	(4)
	\$		%	\$
FRINGE BENEFIT (Rate____)	Total			\$

## Attachment “I” Work Plan Matrix

**Table headings defined:**

- Activity:** What we will do to meet the stated objective?
- Person Responsible:** Who is responsible for making sure that the activity is completed?
- Date:** What is the timeline for this activity and/or tasks?
- Process:** What are the specific tasks that need to be accomplished?
- Tracking Methods:** What are we using to track the completion of the activity?
- Outcomes:** What change are we making? (e.g. new data group meets)
- Outputs:** What is the intensity of activity? (e.g. 1 meeting per month)
- Products/Verification:** What is the final result of the activity?
- Resources:** Who is available to complete the activity (e.g. staff resources)?  
What is available to complete the activity? (e.g. data)

<b>Goal 1.:</b>									
<b>Objective 1.a.:</b>									
Activity	Person Responsible	Date		Process	Tracking Methods	Outcome(s)	Output(s)	Products/ Verification	Resources
		Start	Due						