

Regional Genetics and Newborn Screening Collaboratives

The Genetic Services Branch is in the Division of Services for Children with Special Health Needs, which is part of the Maternal and Child Health Bureau. For more information, call (301) 443-2170 or visit the website, www.mchb.hrsa.gov.

Genetic Services Branch

Activities of the **Genetic Services Branch** help State maternal and child health (MCH) officials, other public health and health care professionals, families and individuals respond to new scientific findings and technologies in the fields of genetics and newborn screening. The activities help to clarify genetic service, resource and policy issues for stakeholders; establish capacity infrastructure for delivering services; improve access to services for medically underserved populations; integrate genetic research and medicine into state programs and their local communities; and develop education and training opportunities in genetic medicine for consumers and health professionals.

Heritable Disorders Program

- The **Heritable Disorders Program** was established by legislation in 2000 “to enhance, improve or expand the ability of State and local public health agencies to provide screening, counseling or health care services to newborns and children having or at risk for heritable disorders.” The legislation created a grant program and an Advisory Committee to the Secretary of the federal Department of Health and Human Services.
- In 2004, the Maternal and Child Health Bureau (MCHB) awarded grants to 7 Regional Collaborative Groups and 1 National Coordinating Center to implement the **Heritable Disorders Program**.

Regional Genetics and Newborn Screening Collaboratives

The purpose of the **Regional Genetics and Newborn Screening Collaboratives** is to enhance and support the genetics and newborn screening capacity of States across the nation by undertaking a regional approach to determine and resolve the needs and maldistribution of genetic resources. These grants are expected to improve the health of children and their families by moving genetic medicine into public health and health care services. The seven regions identified are as follows:

Region 1: New England Regional Genetics Group, including Connecticut, Massachusetts, Maine, New Hampshire, Rhode Island, and Vermont.

Region 2: New York-Mid-Atlantic Consortium for Genetic and Newborn Screening Services, including District of Columbia, Delaware, Maryland, New Jersey, New York, Pennsylvania, Virginia, and West Virginia.

Region 3: Southeast Regional Genetics Group, including Alabama, Florida, Georgia, Louisiana, Mississippi, North Carolina, Puerto Rico, South Carolina, Tennessee, and the US Virgin Islands.

Region 4: Great Lakes Genetics Collaborative, including Illinois, Indiana, Kentucky, Michigan, Minnesota, Ohio, and Wisconsin.

Region 5: Heartland Regional Genetics and Newborn Screening Collaborative, including Arkansas, Iowa, Kansas, Missouri, North Dakota, Nebraska, Oklahoma, and South Dakota.

Region 6: Mountain States Regional Collaborative Center, including Arizona, Colorado, Montana, New Mexico, Nevada, Texas, Utah, and Wyoming.

Region 7: Western States Genetic Services Collaborative, including Alaska, California, Hawaii, Oregon, Washington, and US Pacific Basin.

National Coordinating Center

The National Coordinating Center is at the American College of Medical Genetics. *ACMG offers genetics resources for genetic service providers, primary care professionals, MCH health professionals, the public health community, government policy makers, and consumers. Visit the website, <http://www.acmg.net> or call (301) 634-7127.*

The **National Coordinating Center** (NCC) supports the MCHB-funded Regional Genetics and Newborn Screening Collaboratives projects in their coordination and implementation efforts. The NCC also provides opportunities for community forums between the Regional Collaborative projects, MCHB and other relevant organizational entities. The NCC will help identify and prioritize issues of importance to the genetics and newborn screening community specifically, regarding the utilization of genetic services at the National, State, and community levels.

Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children.

Visit the website, <http://mchb.hrsa.gov/programs/genetics/committee/default.htm>.

The **Committee** provides advice and recommendations to the Secretary of Health and Human Services (HHS) concerning grants and projects and technical information to develop policies and priorities for the Heritable Disorders Program. In addition, the Committee specifically addresses the most appropriate application of universal newborn screening tests, technologies, policies, guidelines and programs for effectively reducing morbidity and mortality in newborns and children having or at risk for heritable disorders.

Other Resources:

The **National Newborn Screening and Genetics Resource Center** offers newborn screening and genetic service resources. Visit the website, <http://genes-r-us.uthscsa.edu> or call (512) 454-6419.

The **HRSA MCHB Genetic Services Branch** provides a newborn screening brochure and additional information for parents and health professionals. Visit the website, <http://mchb.hrsa.gov/programs/default.htm>.

GeneTests-GeneClinics is a publicly funded medical genetics information resource developed for health care providers and researchers. Visit the website, www.geneclinics.org.

The project, **Community Centered Family Health History**, focuses on utilizing family traditions and oral history for health promotion and was developed with a diverse group of partners including disease advocacy, community, and health organizations. Visit the website, <http://www.geneticalliance.org>.

The **Genetic Services Policy Project** describes current models of genetic services delivery, and uses stakeholder perspectives to translate genetics research into practice that will lead to more effective service models. Visit the website, <http://depts.washington.edu/genpol>.

The **National Coalition for Health Professional Education in Genetics** is a coalition of more than 100 health organizations. Visit the website, www.nchpeg.org.

The **HRSA Information Center** offers a wealth of maternal and child health publications and resources. Visit the website, <http://www.ask.hrsa.gov> or call toll-free (888) ASK-HRSA (275-4772).

The **March of Dimes Perinatal Data Center** provides free access to U.S., state, county, and city maternal and infant health data, and allows users to create maps and graphs for specific maternal and infant health indicators. Visit the website, <http://www.marchofdimes.com/peristats>.

The **Genetics Home Reference**, a resource of the National Library of Medicine, provides consumer-friendly information about genetic conditions and the related genes and chromosomes. The homepage also links to information about newborn screening. Visit the website, <http://ghr.nlm.nih.gov> or call (301) 496-0433.