



National Coordinating Center for the Genetics and Newborn Screening Regional Collaborative Groups

FACT SHEET

Background

In 2004 and 2007, the Maternal and Child Health Bureau of the Health Resources and Services Administration (MCHB/HRSA), Genetic Services Branch (GSB) awarded grants to seven Regional Genetic Service and Newborn Screening Collaborative Groups (RCs) and a National Coordinating Center (NCC) as part of larger on-going efforts to improve the health of children and their families by promoting the translation of genetic medicine into public health and health care services. The NCC is formed as a partnership with the GSB/MCHB/HRSA through a cooperative agreement with the American College of Medical Genetics (ACMG). The NCC is organized around a central office and an Advisory Committee. The Advisory Committee includes the seven RCs and representatives of national organizations that serve as resources to the NCC and the RCs.

Goals of the Regional Collaborative Groups and their National Coordinating Center

The RCs work to strengthen and support the genetics and newborn screening (NBS) capacity of the States, and therefore the Nation, using a regional approach to addressing the maldistribution of genetic service providers. A fundamental goal of the program is to improve access to high quality health care services related to newborn screening and genetics within local communities. The NCC enhances the activities of the seven RCs by providing the infrastructure, coordination, technical assistance and resources necessary to address issues of universal importance, thereby avoiding duplication of efforts and allowing the regions to focus on their unique areas of need. The NCC also facilitates collaborations between the RCs and national projects, using local communities to pilot materials and programs for policymakers, health professionals and families. All activities and programs of the NCC/RC system strive to build linkages between primary care providers and medical home, geneticists and other specialty providers, and public health, so that the needs of patients and families with heritable disorders are best served.

NCC Activities

NCC initiatives include:

- 1) Building national capacity in the use of telegenetics
- 2) Establishing a searchable national network of genetic service and subspecialty providers experienced in diagnosis and management of infants detected in NBS programs
- 3) Collecting and disseminating data that establish the value of genetic services to payers and policymakers
- 4) Developing disaster preparedness measures to assure that NBS programs and the treatment of patients with metabolic conditions are not interrupted
- 5) Bridging NBS and genetic testing laboratories with the medical home through development and distribution of management guidelines, including tools pertaining to transition of patients from pediatric to adult care
- 6) Developing resources for State policymakers
- 7) Fostering national data collection efforts, including tracking pilot NBS programs and establishing and maintaining a patient long-term follow-up database and registries useful in rare disease research and service
- 8) Integration of genetics into electronic health systems, including genetics patient information and clinical decision support tools.

Maximizing collaboration between the genetic services, primary care, NBS and public health communities is critical to the success of each effort and the collective impact of the NCC/RC system.

The Regional Collaborative Groups

Region 1: The New England Regional Genetics Collaborative (NEGC), with CT, MA, ME, NH, RI and VT (www.negenetics.org/)

Region 2: New York-Mid-Atlantic Consortium for Genetic and Newborn Screening Services, with DC, DE, MD, NJ, NY, PA, VA, and WV (www.wadsworth.org/newborn/nymac/)

Region 3: The Southeast NBS and Genetics Collaborative, with AL, FL, GA, LA, MI, NC, SC, TN, PR, and USVI (<http://southeastgenetics.org/>)

Region 4: The Region 4 Genetics Collaborative with IL, IN, KY, MI, MN, OH, WI (<http://region4genetics.org/>)

Region 5: The Heartland Regional Genetics and Newborn Screening Collaborative, with AR, IA, KS, MO, ND, NE, OK, and SD (www.heartlandcollaborative.org/)

Region 6: Mountain States Genetics Regional Collaborative Center, with AZ, CO, MT, NM, NV, TX, UT, and WY (www.msgrcc.org/)

Region 7: Western States Genetic Services Collaborative, with AK, CA, HI, OR, WA, and US Pacific Basin (www.westernstatesgenetics.org/)

Resource Partners

NCC Resource Partners include the following organizations:

- American Academy of Pediatrics
- American Health Information Community (HHS)
- Association of Maternal and Child Health Programs
- Association of Public Health Laboratories
- Association of State and Territorial Health Officials
- Eunice Kennedy Shriver National Institute of Child Health and Human Development (NIH)
- Genetic Alliance
- March of Dimes
- National Center on Birth Defects and Developmental Disabilities (CDC)
- National Conference of State Legislatures
- National Newborn Screening and Genetics Resource Center
- Sickle Cell Disease Association of America
- Office of Rare Diseases (NIH)

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