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The HRSA Genetics Collaboratives Are Bringing Genetic and Newborn Screening Services to Local Communities Around the United States

BETHESDA, MD – September 10, 2009 | Overcoming the challenges of bringing quality and cutting edge genetic and newborn screening (NBS) services to local communities and to children and families with hereditary diseases is extremely complex. It requires coordinated, multifaceted and multidisciplinary efforts that are national, regional, and local and include public, private and not-for-profit partnerships. In order to meet these challenges, the Health Resources and Services Administration/Maternal and Child Health Bureau's Genetic Services Branch (HRSA/MCHB/GSB) awarded the American College of Medical Genetics (ACMG) a cooperative agreement in 2004 and later renewed it until 2012 to serve as the National Coordinating Center (NCC) for seven similarly-funded Regional Genetic and Newborn Screening Service Collaboratives known as the HRSA Genetics Collaboratives (www.nccrcg.org).

These seven HRSA Genetics Collaboratives and their NCC are working to improve access to local genetic and newborn screening services, information, and resources for individuals and families with heritable disorders. A major component of the NCC/Genetics Collaboratives system involves using a variety of approaches to link primary care providers, geneticists and other specialist providers, and public health services into a comprehensive medical home that meets all the needs of individuals and families with heritable conditions. Activities at all levels engage consumers and families, with new opportunities for partnerships continually emerging.

"Hundreds of professionals including public health officials, newborn screening program staff members, primary care providers, physician geneticists, genetic counselors, consumer advocates, and families are active in the HRSA Genetics Collaboratives. The Collaboratives are bringing genetic discoveries into local communities in every state in the country. They are working hard to improve local access to newborn screening and genetic services for everyone by addressing the unique needs of the community," says Judith Benkendorf, MS, CGC, a genetic counselor and Project Director of the NCC. "Each regional Genetics Collaborative has fostered a variety of approaches to building linkages between public health, genetics specialists, primary care/the Medical Home and families. Some of their activities are being replicated nationally. A benefit of the current coordinated system is that each HRSA Genetics Collaborative has access to national expertise, positioning it to be a "go to" resource for information about genetic and newborn screening services" added pediatrician Tracy L. Trotter, MD, FAAP, Senior Partner, San Ramon Valley Primary Care.

The NCC also facilitates collaborations between the HRSA Genetics Collaboratives and national projects, using local communities to pilot materials and programs for policy makers, health professionals and families. Many national organizational partners contribute additional resources.

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National Coordinating Center for the
Regional Genetic and Newborn Screening
Service Collaboratives

NCC initiatives include:

- building national capacity in the use of telegenetics;
- establishing a searchable national network of genetic service and subspecialty providers experienced in the diagnosis and management of infants with heritable disorders detected through NBS programs as well as others affected by genetic disease;
- collecting and disseminating data that establish the value of genetic services to payers and policy makers;
- developing disaster preparedness strategies to ensure that NBS programs and treatment of patients with metabolic conditions are not interrupted during the course of emergencies;
- developing and distributing management guidelines and “just in time” resources for providers caring for patients with heritable disorders;
- addressing the transition of patients with heritable conditions from pediatric to adult care; and
- developing resources for state policy makers.

National data collection efforts include tracking pilot NBS programs, collaboration of US and international NBS programs to establish laboratory standards, and establishing and maintaining a patient long-term follow-up database useful in rare disease research. Maximizing collaboration between the genetic services, primary care, NBS and public health communities is critical to the success of each of these efforts and to the collective impact of the NCC and the Genetics Collaboratives.

The Seven Regional HRSA Genetics Collaboratives

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 (NYMAC)**, with DC, DE, MD, NJ, NY, PA, VA, and WV (www.wadsworth.org/newborn/nymac)

Region 3: **The Southeast NBS and Genetics Collaborative (SERC)**, with AL, FL, GA, LA, MS, NC, SC, TN, PR, and USVI
(southeastgenetics.org)

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

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

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

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

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NCC Resource Partners

American Academy of Family Physicians
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 Association of Pediatric Nurse Practitioners
National Center on Birth Defects and Developmental Disabilities (CDC)
National Conference of State Legislatures
National Newborn Screening and Genetics Resource Center
National Society of Genetic Counselors
Office of Rare Diseases (NIH)
Sickle Cell Disease Association of America
Society of Inherited Metabolic Diseases

Note to Editors: The HRSA Genetics Collaboratives are an expert resource for the media. For interviews with individuals at the NCC and regional genetics experts, contact Kathy Beal at 301-238-4582 or kbeal@acmg.net. The NCC website has more information at: www.nccrcg.org

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