

### Seven Regional Genetics and Newborn Screening Collaboratives

Regional Collaborative	States	Grantee Name, Project Investigators* & Other Key Staff	Website & Objectives
Region 1 “NERGG” New England	CT, MA, ME, NH, RI, & VT.	<p>New England Regional Genetics Group, NERGG, Inc. PO box 920288 Needham, MA 02492-0288</p> <p>Thomas Brewster, MD* Anne Comeau, PhD Susan Weisbren, PhD Mary Francis Garber, MS, CGC</p>	<p><a href="http://www.nergg.org">http://www.nergg.org</a></p> <ol style="list-style-type: none"> <li>1. Enhance collaborations among existing genetic and NBS entities and to fully incorporate public health departments and Title V Programs, pediatric societies and families in regional endeavors.</li> <li>2. Evaluate and improve current practice models for genetic services relevant to NBS disorders and to extend these models to non-NBS disorders.</li> <li>3. Develop educational opportunities and evaluate/develop materials too increase genetic literacy among public health personnel, healthcare providers, affected families and the general public.</li> </ol>
Region 2 “NYMAC” New York and Mid-Atlantic	DC, DE, MD, NJ, NY, PA, VA, & WV.	<p>Health Research Inc. New York State Dept of Health 1 University Place Rensselaer, NY 12144-3424</p> <p>Kenneth A. Pass, PhD* Louis Bartoshesky, MD, MPH* Katharine Harris, MBA</p>	<p><a href="#">Web site: TBA</a></p> <ol style="list-style-type: none"> <li>1. Develop regional collaborative partnerships that include all parties interested in genetics.</li> <li>2. Develop and implement local solutions to barriers to access to specialty care by children with congenital conditions.</li> <li>3. Articulate a regional coordinating plan to address the maldistribution of genetic and newborn screening services and expertise across the region.</li> <li>4. Develop regional and interregional (with Regions 1, 3 and 4) back-up agreements for newborn screening in case of emergency shutdown.</li> <li>5. Standardize, as appropriate and possible, newborn screening panels in the region in response to the March of Dimes’ and American College of Medical Genetics’ recommendations and those anticipated from the DHHS Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children.</li> <li>6. Educate primary care medical providers, patients and their families, and medical insurers about the treatment of people with specific genetic conditions. Suggest that the work group include primary medical care providers.</li> <li>7. Develop collaborative partnerships between primary medical care providers, genetic and /or specialty care providers and health insurers to ensure continuity of medical care for children identified with disease by the newborn screening programs within the a medical home.</li> <li>8. Award small grants.</li> </ol>
Region 3 “SERGG” Southeast	AL, FL, GA, LA, MS, NC, PR, SC, TN, & USVI.	<p>SERGG, Inc. PO Box 1642 Decatur, GA 30031-1642</p> <p>David Ledbetter, PhD* Hans Anderssen, MD* Rani Singh, PhD Mary Rose Lane</p>	<p><a href="http://www.sergginc.org">http://www.sergginc.org</a></p> <ol style="list-style-type: none"> <li>1. Identify existing gaps in genetic services in Region 3 affecting health and development of children and adults with heritable disorders.</li> <li>2. Expand existing regional capabilities and resources, and develop new regional systems to address gaps identified in genetic services and maldistribution of genetic resources.</li> </ol>

			<ol style="list-style-type: none"> <li>3. Improve regional communication infrastructure to facilitate information sharing among providers of genetic services, other health care professional, and consumers; and establish collaborative partnerships with other professional organizations.</li> </ol>
Region 4	IL, IN, KY, MI, MN, OH, & WI.	<p>Michigan Public Health Institute 2436 Woodlake Circle Ste 300 Okemos, MI 48864-5940</p> <p>Cynthia Cameron, PhD* Janice Bach, MS, CGC</p>	<p><a href="http://region4genetics.org">http://region4genetics.org</a></p> <ol style="list-style-type: none"> <li>1. Implement universal screening and confirmatory testing of newborns for inborn errors of amino acid, organic acid and fatty acid metabolism; achieve uniformity or testing panel in the region; improve analytical performance.</li> <li>2. Reduce inequities in access to clinical genetic services; telemedicine, long distance consultation, exchange clinics.</li> <li>3. Utilize a regional approach to improve public health infrastructure for supporting optimal diagnosis, follow-up and management of children with heritable disorders and birth defects.</li> </ol>
Region 5 "The Heartland"	IA, KS, MO, NB, ND, OK, SD, & AR.	<p>University of Oklahoma Health Sciences Center 940 NE 13<sup>th</sup> Street, Room B2418 Oklahoma City, OK 73104</p> <p>John Mulvihill, MD* Lori Williamson, MS, CGC</p>	<p><a href="http://heartland.ouhsc.edu">http://heartland.ouhsc.edu</a></p> <ol style="list-style-type: none"> <li>1. Enhance existing services, increase the public's awareness of and access to services, and correct the maldistribution of genetic services that currently exists.</li> <li>2. Develop a regional infrastructure.</li> <li>3. Improve regional collaboration, communication, and shared resources; directory, website, and telecommunications.</li> <li>4. Address regional and national priorities- education, clinical research, newborn screening, public health genetics, and genetic services.</li> <li>5. Fund Practice Models and Pilot Projects that address regional priorities.</li> </ol>
Region 6 "Mountain States"	AZ, CO, MT, NM, NV, TX, UT, & WV.	<p>Mountain States Genetics Foundation 8129 W. Fremont Avenue Littleton, CO 80129-4311</p> <p>John Johnson, M.D* Joyce Hooker</p>	<p><a href="http://www.mostgene.org">http://www.mostgene.org</a></p> <ol style="list-style-type: none"> <li>1. Establish the MoStGeNe Regional Center.</li> <li>2. Update and regionalize the existing needs assessment.</li> <li>3. Develop a regional plan for collaborative genetics activities.</li> <li>4. Fund small grants</li> <li>5. Identify models of best practice.</li> </ol>
Region 7 "Western States"	AK, CA, Guam, HA, ID, OR, & WA.	<p>State of Hawaii Department of Health 1250 Punchbowl St #307 Honolulu, HI 96813</p> <p>Sylvia Au, MS, CGC* Kerry Silvey, MA, CGC*</p>	<p><a href="http://www.westernstatesgenetics.org">http://www.westernstatesgenetics.org</a></p> <ol style="list-style-type: none"> <li>1. Establish and maintain the infrastructure needed to support the Western States Regional Genetic Services Collaborative activities.</li> <li>2. Plan, pilot and evaluate a regional practice model that improves access to specialty genetics services, comprehensive primary care, and care coordination for Hawaii, Idaho, and Oregon children with heritable conditions. Services for Alaska and Nevada children may be added in subsequent years.</li> <li>3. Increase the capacity of Alaska, California, Hawaii, Idaho, Nevada, Oregon, Washington, and Guam genetics and newborn screening programs to perform their assessment, policy development, and assurance functions.</li> </ol>

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