

ABSTRACT

Project Title: The Mountain States Regional Genetics Network

Applicant Organization Name: Texas Health Institute

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Problem: The mountain states region (Arizona, Colorado, Montana, Nevada, New Mexico, Texas, Utah, and Wyoming) is challenged to deliver genetic services to underserved populations, many of whom are culturally distinct from the majority population. This vast geographic region is predominately composed of HRSA-designated medically underserved areas, with relatively few genetic centers, creating an additional challenge to the region.

Priorities and Goals: The overall program goal of the Mountain States Regional Genetics Network (MSRGN) is to ensure that individuals with heritable disorders and their families have access to quality care and appropriate genetic clinical services. MSRGN will focus on 3 program priorities to achieve this goal over the next 4 years: 1) support a regional infrastructure for the genetics health care delivery system; 2) provide education-related activities for providers, families, individuals, and other stakeholders; and 3) facilitate the use of telehealth and telemedicine in the genetics health care delivery system.

Methodology: MSRGN will address program priorities through our state-based team model in which individual, multidisciplinary state teams identify and address barriers that limit the availability of genetic services within their state. Targeting underserved populations (rural, Hispanic, American Indian), we will utilize and expand existing telehealth infrastructure, emphasizing training of genetics providers and technical assistance (TA) to facilitate implementation. Increased initial genetics evaluation and referrals by primary care providers will be fostered through awareness of MSRGN resources, including diagnostic testing algorithms, webinars and virtual education series, in collaboration with their professional organizations. A “40 Clinic Initiative” will engage primary care practices that serve target populations for focused TA and education. MSRGN’s empowered and committed consumers serve in leadership roles and will directly engage, educate and support their communities through the Genetic Ambassadors and Genetic Navigator programs, using grassroots (Genetic Pop-Ups) and other forums. Social media will be leveraged for consumer education and increased awareness of genetics resources. An annual Genetics Summit will foster cross-regional collaboration, education, and networking.

Coordination: The MSRGN management team will oversee all network activities and will coordinate and facilitate the activities of the state teams. An advisory committee will provide broad programmatic, non-clinical, and budgetary oversight. MSRGN staff and partners will collaborate with the other regional networks, the Advances in Integrating Genetics into Clinical Care program (AIGCC) and National Genetics Education and Family Support Program (NGEFSP).

Evaluation: MSRGN will use an external evaluator to conduct a formative, outcome-based program evaluation that will demonstrate regional success in achieving stated objectives to improve access to genetic services.