

OVERVIEW OF STATE TEAMS

MSRGN Mission

To ensure that individuals with genetic disorders and their families have access to quality care and appropriate genetic expertise and information through facilitating a professional network of genetics clinics, key primary care practices, consumer advocates, and state health department resources.

History of MSRGN

The eight states in the Mountain States region (Montana, Wyoming, Colorado, Utah, Nevada, Arizona, New Mexico, and Texas) have a combined area of over one million square miles, constituting a land mass of almost one third of the entire United States and extending from Canada to Mexico. The Mountain States region has a population of more than 49 million people. Overall there are 491 counties within the Mountain States, 199 of which meet frontier criteria (fewer than seven persons per square mile). Five of the states have larger concentrations of Hispanic/Latino populations than the US average, and the Mountain States region is home to a higher percentage of American Indians than the US as a whole. More than 700,000 births occur annually within the Mountain States region, and it is estimated that three to five percent of these births are complicated by a genetic or congenital condition.

MSRGN was first funded in 1984 through HRSA, Genetics Branch which funded 10 regional networks throughout the US including territories (Guam, and Puerto Rico). These regional genetics networks were established in response to the state newborn screening programs within the state health departments. It was soon recognized by HRSA the need for the regional networks to provide a forum for states around issues in the quality and implementation of the newborn screening program. With the current grant cycle, HRSA has taken a change in focus to ensure that underserved individuals with genetic disorders and their families have access to quality care. To date, seven regional networks continue to meet the needs of the states and HRSA requirements.

State Team

MSRGN seeks to understand and broker communication between entities and understand the potential state-based "network" for genetics. In order to achieve this in this grant cycle, a state-team based model has been implemented in each of the eight states in the region.

These teams will collaborate to define the challenges for their specific underserved populations and to identify state-based resources, supported by input and collaborative learning from other states' experiences as the state teams interact



through MSRGN. State Teams will also assist with implementation and dissemination of strategies as developed across the region to improve access to genetic services within their state. A modest budget of \$1200 will be provided for each State Team to facilitate meetings, provide in-state travel for key stakeholders, support educational presentations for partner organizations, to establish data collection, and/or other activities as needed locally.

MSRGN staff will work closely to provide support, consultation, and facilitate connections with the State Team leads. The intention of MSRGN's involvement is to strengthen the state team in an effort to create a team that is ultimately able to be self-sustaining.

Each State Team will have a lead or co-leads.
The team may consist of the following:

- State Department of Health (NBS, genetics program if it exists)
- Title V/Children with Special Healthcare Needs programs (healthcare programs/coordinators)
- State Medicaid program representative
- Genetics provider representative (physician/nurse/genetic counselor)
- Primary care provider/Pediatrician
- Community support group representative (e.g. Family to Family, Family Voices, or disease specific)
- Consumer or family member of consumer

State Team's Relationship with MSRGN

The work of the state team membership will be carried out through monthly state team calls to share progress and challenges on projects selected by the State Team. State Teams will have the opportunity to participate at in-person forums (Genetics Summit and Mid-Year State Team Meeting), where they can meet face to face with their own teams and with other state teams in the region.

MSRGN's Relationship with State Teams

All members of the State Team are volunteers MSRGN appreciates and recognizes their time, dedication and work on the team projects. Because of this, MSRGN staff is dedicated to assisting the teams in making progress on their project goals.

MSRGN will work with team leads or co-lead individually to prepare for State Team calls and strategize project goals. MSRGN will set up monthly Zoom video conference link, send out calendar invite to State Teams and MSRGN management team. State team leads or co-leads will help facilitate the State Team's discussion on monthly calls. Monthly call minutes will be taken and distributed by MSRGN.



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