

OVERVIEW OF MSRGN 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 (Arizona, Colorado, Montana, Nevada, New Mexico, Texas, Utah, and Wyoming) 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. HRSA soon recognized the need for the regional networks to provide a forum for states around issues in the quality and implementation of the newborn screening programs. In 2017, HRSA took 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 territories and HRSA requirements.

State Team

MSRGN seeks to understand and broker communication between involved stakeholders and understand the potential state-based "network" for genetics. In order to achieve this, a state-team based model was implemented in each of the eight states in the region starting in 2018 and will continue in this new grant cycle.

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 self-sustaining.

Each state team will have at least two co-leads.
The team may consist of the following members:

- Pediatrician
- Geneticist
- Genetic Counselor
- Primary Care Physician/Provider
- Nurse
- Consumer/Family member
- Consumer/Family Member representing the underserved community identified by each state team
- Family Leader (e.g. Family to Family, Family Voices, or disease specific)
- Self-Advocate (individual living with genetic condition)
- Early Childhood Education Part C Partner
- Public Health - Newborn Screening
- Public Health - Title V
- Medicaid Representative
- Telehealth Representative (office of rural health, broadband committee, etc.)

Relationships

MSRGN's Relationship with State Teams

All members of the state teams 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 the co-leads individually to prepare for state team calls and strategize project goals. MSRGN will set up monthly Zoom video conference links and send out calendar invites to state team members and the MSRGN management team. State team leads or co-leads will help facilitate the state team's discussion on monthly calls. Monthly call agendas and minutes, as prepared by members of the state teams, will be distributed by MSRGN along with the call invites and zoom information.

State Teams' 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 each 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. Monthly call agendas and minutes will be created by designated members on the state team.

Expectations

MSRGN's Expectations of the State Teams

- Each state team will be led by 2 co-leaders.
- Each state team will consist of members representing genetic and primary care practitioners, public health professionals and consumers.
- Each state team will strive for a balanced geographical representation of their state.
- Each state team member will make an effort to attend the monthly state team call and if they are unable to attend, they will let the co-leads know of their absence.
- Each state team member will be an active participant on the team, lending their expertise to ongoing projects and team discussions.
- Each state team will spend their \$1200 yearly.
- Each state team will assist MSRGN in obtaining the program priorities stipulated by HRSA.

State Teams' Expectations of MSRGN

- MSRGN will have staff available to support the state teams and co-leads to facilitate the infrastructure and logistics of the state team model.
- The state teams can expect that MSRGN will:
 - set up zoom call-in information for recurring monthly meetings (once date is confirmed by team and co-leads);
 - send out calendar invites for monthly recurring calls;
 - send out reminders for call days before the calls with agendas and minutes from previous calls (as provided by the co-leads); and
 - keep an updated roster/state teams list (with updates provided by members and co-leads to MSRGN staff).
- MSRGN will offer support in conjunction with THI in reimbursing expenses, paying invoices, and other fiscal duties, once expenditures have been approved by the state team and MSRGN management team.
- MSRGN will provide up-to-date information about genetic programs, resources and individuals, from a national and regional perspective.

Benefits

Benefits received by the State Teams partnership with MSRGN

- Have a forum to discuss genetic services in the state.
- Opportunity to meet and network with colleagues within in their state, across our 8-state region and nationally.
- An opportunity for the data gathered from their state team projects to be represented in a national data set.
- Modest state team funding available to fund state team projects.
- Empowerment to determine and identify genetically underserved populations and barriers to genetic care for their state.
- Opportunity for a few state team members to travel to in-person regional meetings including the Genetic Summit.
- Receive a monthly PD Message from MSRGN, to keep members updated on information about our region.

Benefits received by MSRGN by partnering with State Teams

- MSRGN is able to collect and analyze data created from state team projects.
- State teams fulfill our federal grantor's requirement of supporting a regional infrastructure for the genetics health care delivery system.
- State teams form the core membership of the MSRGN network.
- The State teams represent a grass roots approach to informing MSRGN of what is going on at the systems level related to genetic services delivery for that state.
- The State teams give equal coverage and equal voice to each state in our region.
- The State teams provide a rapid feedback and dissemination mechanism for important and timely information in our region.

State Team Funds and Project Examples

- The Arizona and Texas state teams organized conference booths and advertising which promoted MSRGN's genetic resources to local professional societies that represent pediatricians and primary care providers (AAP, TPS, NAPNAP etc.).
- The Colorado state team designed, printed and distributed magnets promoting MSRGN's website and state team resources.
- The Montana state team partnered with an in-state organization who provide a digital medical passport for children with genetic disorders or other medical complexities.
- The Montana state team utilized gas cards to support travel of families from remote underserved areas of the state to attend a family-to-family-health information and medical transition conference.
- The Nevada state team convened an in-state meeting with members of the state team to focus on identifying barriers to genetic care in their state and plan for initiatives to address these barriers
- The Nevada state team designed and printed educational materials, postcards for primary care providers on genetic referrals and newborn screening, brochure on Careers in Public Health Genetics , for dissemination to primary care practices in the state.
- The New Mexico state team conducted a family survey about barriers to accessing medical services for children with a suspected genetic condition and other special healthcare needs. This survey included families who represented underserved populations including tribal representation.
- The Texas state team purchased online advertising and promoted MSRGN resources to nurse practitioners.
- The Utah state team provided a training session for pediatricians on implementing the Utah specific developmental delay algorithm at 2 clinics in Utah and followed up with a survey a year later to monitor the progress.
- The Wyoming state team purchased iPads and laptops for use in the telegenetics clinics.



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