



MSRGN STATE TEAMS AND STEERING COMMITTEE MEETING
OVERVIEW OF GRANT OBJECTIVES
JANUARY 10-11, 2018



MSRGN Mission

2017-2020

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.



Program Priorities and Objectives

- Link medically underserved populations to genetic services;
- Implement quality improvement activities to increase genetic services to the medically underserved;
- Implement telehealth/telemedicine focused on clinical genetics;
- Distribute resources to providers (genetics & primary care), public health professionals, and individuals with genetics conditions and their families.

The challenge is developing a **service infrastructure** throughout our region **to facilitate access** to services for the underserved, creating **sustainable solutions** in our states.



Strategic Plan Goal 1: link medically underserved populations to genetic services

- Establish state-based teams with representation from key stakeholders including providers, healthcare systems, public health, and consumers.
 - Identification of needs and resources at state level
 - Dissemination of educational and other resources
 - Conduct regional and national initiatives in each state
- Within Year 1:
 - Identify principal participants in the state teams and establish each state team
 - Begin to populate individual state pages on MSRGN website with state-specific information and links, to include links to regional and national resources
 - Meet (here and now)!



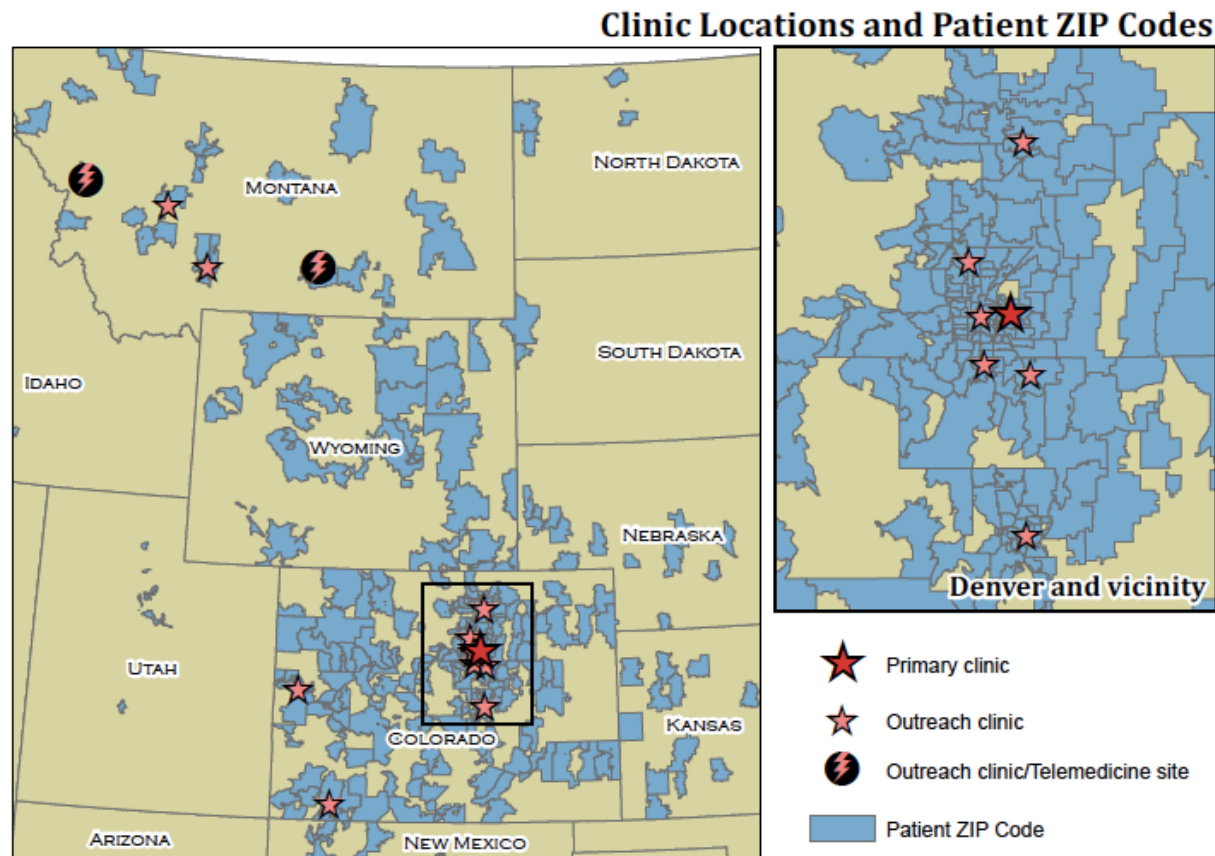
Strategic Plan Goal 1: link medically underserved populations to genetic services

- Engage genetics clinics in Texas, Colorado, and Montana and establish a relationship with Indian Health Services in Arizona and New Mexico.
 - Year 1 target populations to include:
 - Tuba City, AZ
 - Durango and Grand Junction, CO
 - San Antonio, TX
 - Underserved Populations Project (UPP Project)
- Identify other “high potential” opportunities (centers with outreach structures, community service centers, etc) and prioritize opportunities based on improvement potential.
- Completion of the MSRGN Mapping Project.



UPP Project: Data Collection & Review

The Children's Hospital Colorado



- MSRGN's initial work was to collect patient zip code from genetics clinics throughout our region and map in comparison to the known genetics clinics.

Strategic Plan Goal 2: implement QI activities to increase the connection with genetic services for the medically underserved

- QI team: Liza Creel and Kathryn Hassell with consultative support from Chuck Norlin, MD, Director of UPIQ, a state-wide primary care QI network in Utah.
 - Apply QI methodologies to Network activities (e.g. root-cause analysis)
 - Introduce QI processes and provide technical assistance for implementation of improvements in access in local areas (e.g. PDSA cycles for practices)
 - Partner with state-based primary care QI networks, members of the National Improvement Partnership Network in Utah, Arizona and New Mexico, and other potential organizations (e.g. AAP) for dissemination of genetics education and decision support tools for primary care practices
- Participate in NCC in-person/virtual QI training activities and national projects as determined by NCC with a likely focus on telehealth.



Strategic Plan Goal 3: implement evidence-based innovative models of telegenetics

- In collaboration with the Telehealth Resource Centers, Heartland RGN, and Western States RGN, offer technical assistance and training opportunities for providers and new clinics including an in-person training session at the annual Genetics Summit.
- In conjunction with Metabolic University, develop a telehealth training curriculum for metabolic dietitians.
- Implement telegenetic clinics within the region with QI projects and evaluation to assess outcome.
 - Consistent telegenetics clinics to sites in Montana and Colorado
 - Development of a contract between Tuba City, AZ and CO
 - Technical assistance to Utah and WY



Strategic Plan Goal 4: provide resources to genetic service providers, public health officials, and families

- New interactive MSRGN website to warehouse educational materials, tools, and links to resources to be used by providers, consumers, and public health professionals.
- State-based teams to link resources within each state to facilitate awareness of programs available to individuals and families in their catchment area.
- Annual Genetics Summit with broad representation of multiple stakeholders.



Strategic Plan Goal 4: provide resources to genetic service providers, public health officials, and families

- Promote use of the Medical Home Portal.
- Develop Project ECHO presentation on common reasons for genetic evaluation.
- Work closely with NCC and National Genetics Education and Family Resource Center to develop new educational materials and promote family/consumer engagement.
- Develop evaluation algorithms for primary care providers.
- Social media campaign to increase culturally competent knowledge of genetics.





Winter in Arizona!

QUESTIONS?