

MSRGN STATE TEAMS MEETING
FEBRUARY 14-15, 2019
OVERVIEW OF GRANT OBJECTIVES



Alternate Title ---



What we said we would do and what we have done!



MSRGN Mission 2017-2020





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







- 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.
 - To identify needs and resources at a state level, disseminate educational and other resources, and conduct regional and national initiatives in each state.

Years 1 and 2:

- DONE -- state teams established and working hard!
- Populated individual state pages on MSRGN website with state-specific information and links including links to regional and national resources.
- State team projects identified and ongoing stayed tuned!



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.
 - Underserved Populations Project (UPP Project).
 - Webinars to IHS and San Antonio, TX primary care providers.
- •Identify other "high potential" opportunities (centers with outreach structures, community service centers, etc) and prioritize opportunities based on improvement potential.
 - To be discussed further where do we go from here?
- Completion of the MSRGN Mapping Project.
 - Able to identify additional underserved areas and genetic resources within our region.



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



Years 1 and 2:

- Monthly calls with the QI team with the added involvement of Kristi and oversight by Dr. Marci Sontag.
- Continue to look for QI activities throughout our projects.
- Newest project is our Facebook Live project directed by Kristi.
- QI team will continue to work with each state team on projects helping with assessment and technical assistance.
- More to come tomorrow!



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.



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



• Telegenetics clinics:

- Consistent telegenetics clinics from Children's Hospital Colorado to sites in Montana and Colorado and from University of Utah to Wyoming.
- Expansion of Colorado sites to include Montrose and Glenwood Springs and in-home telegenetic visits.
- Contract between Pueblo Co Dept of Public Health and Environment and MSRGN to support nurses for new telegenetics clinic in Pueblo, CO.
- Contract (finally) completed between Tuba City Regional Health Care Corporation and University of Colorado to begin telegenetics clinics in Tuba City, AZ.
- Ongoing technical assistance to Utah, Montana, and Wyoming.
- Discussions ongoing in New Mexico to consider telegenetics.



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



•Telegenetics training:

- MSRGN Genetics Summit (Oct, 2018) ½ day telegenetics training in collaboration with SW Regionals Telehealth Resource Center and Western States Regional Network.
 - 57 participants
- MSRGN supported provider training three attending upcoming training in April.
- Telehealth presentation at Metabolic University (RDs).
 - 33 participants
- Telegenetics training to be offered again at upcoming Genetics Summit.



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 ongoing updates!
- •State-based teams to link resources within each state to facilitate awareness of programs available to individuals and families in their catchment area ongoing!
- •Annual Genetics Summit with broad representation of multiple stakeholders great success in 2018; next summit planned for fall, 2019.





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

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- Promote use of the Medical Home Portal.
- Develop Project ECHO presentation on common reasons for genetic evaluation stay tuned to hear from CO state team.
- •Work closely with NCC and National Genetics Education and Family Resource Center to develop new educational materials and promote family/consumer engagement always!
- •Develop evaluation algorithms for primary care providers what's next?
- Social media campaign to increase culturally competent knowledge of genetics –
 Facebook Live presentations, Genetic Ambassadors program,
 ongoing Facebook posts and twitter posts.



Happy Valentines' Day!!

QUESTIONS?



MSRGN State Teams:





The heart beat of our region! We thank you!