



## 2012 Annual Newsletter Mountain States Genetics Regional Collaborative

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### Greetings!

It has become an annual tradition for MSGRC to end the fiscal year with a more extensive message (the "newsletter") than our usual monthly message from the Project Directors. This year's newsletter was delayed by events around the renewal of our grant from Genetic Services Branch at HRSA, but we believe you'll find it was worth waiting for!

### Reflections: Look How Far We've Come!

Once again, we have bid farewell to another productive and enlightening year in the Mountain States. Not only have we concluded the year, we've also completed the five-year funding cycle that has supported the Mountain States Genetics Regional Collaborative (MSGRC). The evolution of the MSGRC over these years was both challenging and rewarding, and we are grateful to have had each of you as partners in this process. Over the last five years:

- MSGRC hosted 5 annual meetings, 41 workgroup meetings, 2 emergency preparedness tabletop exercises, and 2 Medical Home Visiting Professorships.



Members of the MSGRC Emergency Preparedness Workgroup meeting during the Annual Meeting in July 2011.

- There have been 11 peer-reviewed publications, 13 platform presentations, and 6 poster presentations highlighting work in the Mountain States. Visit our publications list [here](#).
- We have engaged many new partners and sustained long-term professional relationships that have been in place for countless years.
- MSGRC has increased the number of genetic services visits provided to people with or at risk for heritable disorders through distance strategies, specifically through use of existing telemedicine infrastructure.
- MSGRC has increased the percentage of states/territories in the region with collaborations facilitated by the RC between primary care providers (PCPs) and specialty providers to improve care coordination for people with heritable disorders.
- All states in the region screen for the original conditions included in the Recommended Uniform Screening Panel (RUSP) and most have passed laws, made recommendations, or are exploring opportunities to add screening for Severe Combined Immunodeficiency Disorders (SCID) and Critical Congenital Heart Disease (CCHD).
- Many of our partners have represented the MSGRC on regional and national workgroups including those of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC), the Newborn Screening Translational Research Network (NBSTRN), and the National Coordinating Center for the Genetic and Newborn Screening Service Collaboratives (NCC).

Thank you to each and every one of you - our partners and collaborators - that believe in our mission and continue to volunteer your time and expertise to accomplishing that mission.

### Moving Forward: Look Where We're Headed!

We are excited to announce that we have received notice that the MSGRC will continue to be funded for the next five years! This new grant cycle will represent an expansion of our regional work from previous years and will focus on fulfilling the following eight priority areas:

**MSGRC Program Priority 1:** Enhance collaboration within MSGRC, with National Partners, and with other Regional Collaboratives;

**MSGRC Program Priority 2:** Treat genetic disorders (and risk factors) in the context of a medical home;

**MSGRC Program Priority 3:** Contextually use the role of cultural competence and diversity to adopt innovative outreach projects;

**MSGRC Program Priority 4:** Build capacity in state public health departments to enhance and sustain the delivery of newborn and child screening and genetic follow-up and treatment services;

**MSGRC Program Priority 5:** Strengthen public-private partnerships, communication, and collaboration;

**MSGRC Program Priority 6:** Collaborate and partner with HRSA MCHB-funded programs that promote the scaling up of effective practices;

**MSGRC Program Priority 7:** Expand state and regional collaborative systems of cohorts of patients for long-term monitoring and analysis of follow-up and treatment; and

**MSGRC Program Priority 8:** Continue to address Emergency Preparedness with state laboratories, clinical genetic centers, and families.

We will continue support of our four workgroups - Newborn Screening, Consumer Advocacy, Emergency Preparedness, and Telemedicine - and we are organizing two new workgroups, Medical Home and Health Information Technology, to help us meet the goals of the new grant. We anticipate recruiting many new partners, including those from community-based organizations, local and state government, and other HRSA-funded programs.

In the new cycle, we will also continue support of innovative mini-projects in the region. In the first year, we have two projects that are in their final stages: the Billings Clinic telemedicine project in Montana and the transition project at University of Colorado School of Medicine, which is entering its final year. We will continue to host the Metabolic Consortium and fund the Metabolic Newborn Screening Long-term Follow-up Project. We also plan to continue support for telemedicine activities that expand genetic

counseling services to metabolic and hearing loss patients in Colorado and Wyoming and to improve communication and follow-up with families of Native American children and adults with special needs. We will support several new projects, including a Hemoglobinopathies Long-term Follow-Up Project, the Mountain States Medical Home and Family Partnership Project, and a small project Improving Access to Services for Children with Special Health Care Needs in Native American Communities of Northern Arizona. In future years, we hope to find the opportunity to issue requests for proposals for new mini-projects that help the MSGRC achieve its mission.

We are currently working to identify dates for a rescheduled annual meeting, which we expect to hold sometime in early 2013 when we would usually host our mid-year workgroup meetings. Each workgroup is essential to our activities, so we are exploring opportunities to convene the workgroups and project teams during the fall of 2012. As dates and locations are confirmed, we will update you all so you can mark your calendars and have plenty of time to submit for travel approval through your organization.

#### Part-time Project Coordinator Position Opening

Finally, we'd like to let you know that we are expanding our staff team! The MSGRC has just announced a job opening for the Project Coordinator to support the management team and workgroup activities. Please click [here](#) for information about the position and to find out how to apply.

The priorities for our new five-year grant cycle were developed after extensive national and regional planning including many of you. We believe they reflect the needs of the Mountain States, and we are especially excited about the focus on access to services in our large and diverse region. We could not have even envisioned these ambitious activities without you, and we will need your energy, commitment and counsel to bring them to life. All of us on the MSGRC Management Team are ready to begin the "new years", and we look forward to sharing MSGRC successes with you - the people who make them possible.

Warm regards,

The MSGRC Management Team

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