



Message from the Project Directors Kathryn Hassell, MD & Janet Thomas, MD

November 2019

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Dear Friends and Colleagues,

We would like to wish everyone a Happy Thanksgiving! We would like to thank all the State Teams and our partners for the all the work you do for the Mountain States Regional Genetics Network. We hope that you and your families have a wonderful Thanksgiving.

Your Input Requested

We are excited to share with all of our stakeholders the recently released Notice of Funding Opportunity Announcement (NOFO) for the new cycle that will begin June 2020. The application for the new cycle will be for the Regional Genetic Networks (RGNs). The Mountain State region will continue to cover our current eight states: AZ, CO, MT, NM, NV, TX, UT and WY.

The main areas of focus for the RGN's include:

1. Support a regional infrastructure for the genetics health care delivery system.
2. Provide education-related activities for providers, families, individuals, and other stakeholders.
3. Facilitate the use of telehealth and telemedicine in the genetics health care delivery system.

To access the NOFO click [here](#).

MSRGN is asking for input on the application for the new cycle: Please share your ideas with us as an individual or state team by filling out this [survey](#).

Genetics Pop-Ups Application Now Open!



After successfully launching 5 genetics pop-ups in the spring of 2019, we are excited to announce that we have allocated funding for another round of 8 more Genetic Pop-Ups for 2020 with a goal of awarding one to each state in our region. We are launching this new round with a theme of RARE DISEASE DAY 2020, observed on February 29, 2020. If you are interested in applying click [here](#).

If you are unsure of what a genetics pop-up is and would like to learn more and consider applying to host one, please check out this [PAGE](#) on our website to learn more and see photos from previous pop-ups.

State Team Spotlight: Montana

The Montana Team will be purchasing clinic equipment to expand outreach and telegenetics clinics through Shodair, and will be providing gas cards for families to attend the Montana Transition conference. This [Transitions conference](#) is for youth with disabilities, their parents/guardians, teacher and service providers and is being held on November 18-20, 2019 in Helena, MT. The team is providing support for the development of a web-based Pediatric Medical Passport or MP2 app (a [HRSA funded innovation project](#)). The MP2 app will be available for families with children with special health care needs and is an innovative cloud-based care coordination tool focused on providing information at the right time for families and providers in urgent and emergent care settings.

Archived Recordings of Colorado State Team Newborn Screening Virtual Education Series

The Colorado State Team Newborn Screening Virtual Education Series was designed to help educate primary care providers and interdisciplinary health care teams on genetics and newborn screening conditions. The current sessions will include a review of current newborn screening disorders screened by the Colorado Newborn Screening Program for Colorado and Wyoming. Archived recordings for the following session 1) Inborn Errors in Metabolism 2) Hemoglobinopathies and Endocrine Disorders 3) Cystic Fibrosis and Severe Combined Immunodeficiencies (SCID) can be found [here](#).

Utah State Team adapted Developmental Delay Algorithm

The Utah State Team is working with a couple of pediatric practices in Salt Lake City, Utah area to pilot the Utah developmental delay algorithm the team has adapted to include local resources and referral assistance. The documents can be found [here](#).

Archived Recordings of Nevada State Team ECHO

The Nevada State Team partnered this past summer with Project ECHO Nevada, the Nevada Cancer Coalition and the Nevada State Public Health Lab to offer educational series on Genetics. Two of the four part series has been archived and is available to watch: 1) Cancer as a Genetic Issue 2) Neonatal and Pediatric Genetic Screening. The archived webinars can be found [here](#).

Featured Webinar

Are you looking for relevant webinars to our region on #genetics topics? Check out our Facebook Page, we post upcoming webinar announcements weekly as well as links to archived ones.

Recently, Don Bailey, Ph.D. presented on a webinar on Newborn Screening for Fragile X Syndrome and Other Developmental Disabilities. If you were unable to participate in the webinar, it can now be accessed [here](#).

FOLLOW MSRGN ON TWITTER

MSRGN is now on Twitter. Please follow us [@GeneticMtnState](#)

Warm regards,



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www.MountainStatesGenetics.org

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