





March & April 2018

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Dear Friends and Colleagues,

Happy Spring from all of us at MSRGN! We have had a busy winter as we launched many projects around the region, in collaboration with many of you.

2018 Genetics Summit



Mark your calendar now for this event! Many more details are in the works and will be forthcoming.

Come to San Antonio to gather with individuals with an interest in genetics, including genetics providers, primary care physicians, consumers, and public health professionals.

We are planning a variety of educational activities (offering CMEs/CEUs) and networking opportunities, with a focus on access to genetics care and other MSRGN activities.

You can keep an eye on this <u>page</u> of our website as we finalize the agenda. Information regarding registration, travel and lodging can be found in our newsletter.

DNA Day 2018: April 25th

Join us in celebrating <u>National DNA Day</u>. National DNA Day celebrates the discovery of DNA's double helix in 1953 and the successful completion of the Human Genome Project 15 years ago (in 2003). Look how far we have come!

Each day on the MSRGN Facebook <u>page</u> we are sharing #15for15, which are 15 advances in genetics over the last 15 years since the Human Genome Project Completion. Come check them out and share them on your Facebook page to let others know about the exciting world of Genetics! You can see all the 15 days (as they are revealed) <u>here</u>.

To see if there is a DNA Day event near you (or to submit an event) click <u>here</u>.

Educational Activities

MSRGN is partnering with Indian Health Services to provide educational outreach to primary care providers on the Navajo Reservation in Tuba City, AZ. The first webinar will be presented by Dr. Austin Larson on May 3, 2018 at 2pm CDT. This <u>webinar</u> will discuss the recent advances in genetic testing and their implications for diagnostic testing strategies for children with suspected genetic conditions. For information regarding this webinar click <u>here</u>.

To register for the webinar click here.

UPP Progress

Our Underserved Patient Populations Project (<u>UPP</u>) is moving forward with implementations, addressing areas of greatest need identified during the early phase of this project.

For the Colorado sites of Grand Junction and Durango we continue to work on the development of an algorithm for genetic testing of individuals with developmental delay, targeted to primary care providers. The goal of the algorithm is to help guide primary care providers to begin the genetics evaluation of a child with developmental delay. This will get the process started and help address the long wait times for genetic appointments. We are also gathering additional information to help families navigate the Colorado Medicaid waiver process. This information will be posted on the MSRGN website when completed.

For our Texas site, San Antonio, we are developing a quide for insurance authorization for genetic testing, also targeting primary care providers, to aid in earlier diagnostic evaluation for children in whom there is a concern of a genetic diagnosis. Learning how to obtain insurance approval for testing is a necessary step in obtaining such testing and primary care offices will likely need to become involved in this process to increase the timeliness of diagnosis for their patients.

Finally, direct patient care services were desired by our Tuba City, AZ site. Consequently, a clinical care contract to provide telehealth clinics between the University of Colorado and the Tuba City Regional Health Care Corporation (TCRHCC) has been finalized. Clinics will be started as soon as credentialing and privileges are completed. Tuba City providers also requested additional educational curriculum for providers, as noted above, and materials for consumer focused basic genetic education and literacy are also being developed.

Naturally, resources developed for one site will be made available to all of the region and possibly nationally to other genetic networks and the National Coordinating Center (NCC). The UPP pilot sites will serve as a template for implementation of similar projects

across the region to increase access to genetic services more broadly. Our early work on the UPP project was recently presented at the American College of Medical Genetics Annual Meeting in Charlotte, NC in a poster presentation entitled, "The MSRGN Underserved Patient Populations Project: A Systematic Approach to Identifying and Addressing Barriers to Accessing Genetic Services."



Janet Thomas, MD at ACMG Annual Meeting

State Teams at Work

The backbone of our three-year plan is the development of state teams to identify underserved populations in each individual state and develop and implement projects to address identified state needs. We are excited to announce that our state teams are well staffed with enthusiastic volunteers from all stakeholder groups and are busy identifying projects on which to focus. We are thrilled with the variety of ideas that have been put forth to address access to genetic services and are excited to see the projects develop. We will keep you posted on these projects in future messages.

State teams will have a chance to meet in person just prior to the Genetics Summit, later in the year, to share successes and lesson learned.

As always, if you are not a part of a state team and are looking for a way to get involved with MSRGN in your state, please reach out to us here so we can connect with you and help you get more involved.

As the days grow longer and the weather more spring-like, we look forward to planting many seeds around the Mountain States Region that will lead to better access to improved genetics services for those who live in our Region.

Warm regards,

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