



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

**November 2018**

**Join Our List.**

[Join Our Mailing List!](#)

Dear Friends and Colleagues,

Happy Thanksgiving! As we prepare to celebrate, we would like to take the time to thank our State Teams and partners for all the hard work you do for the MSRGN network. We hope that you and your families have a wonderful Thanksgiving Day!

### **State Team Spotlight: Wyoming**

The Wyoming State Team purchased iPads to use at their two telegenetics clinics in Cheyenne and Casper. The iPads were used for data entry for Phase one of their project which included data collection from the client survey questionnaire developed by the team. Phase two consisted of focus groups with the front line nurses. The team is entering Phase three during which they will conduct an expert interview in December with Dr. Longo. All this data and information will then be compiled and analyzed to assess their new telegenetics clinic program.

### **Colorado State Team at El Grupo Vida Conference**

The Colorado State Team had a resource table at the [El Grupo VIDA](#) conference on October 20, 2018. The team provided families with information on MSRGN and answered questions about basic genetic disorders. Mary Ann Coffman, from [Heartland Regional Genetics Network](#), presented on specialized medical care needed for children with disabilities, including those with genetic conditions. In addition, the Colorado State Team is exploring other financial resources to assist with their ECHO project.

---



*(Mary Ann Coffman, Jesus Castillo, Maria Castillo, and Stefan Mokrohisky)*



*(Mary Ann Coffman)*

## Genetic Ambassador Program

The [Genetic Ambassador Program](#) was launched on November 14, 2018. This program provides opportunities for consumers of genetic services to participate in our genetic network through 1) participation on State Teams 2) participation in MSRGN special projects 3) participation in sharing website and social media resources, in their online communities and 4) through "Genetic Pop-Ups" (more info coming in 2019, stay tuned). A Facebook group has been created to allow Genetic Ambassadors to connect and collaborate online. Please email [Kristi Wees](#) if you are a consumer, advocate, individual with a genetic condition, family member or family leader in our region (AZ, CO, MT, NV, NM, TX, UT and WY) and would like to become a Genetic Ambassador.

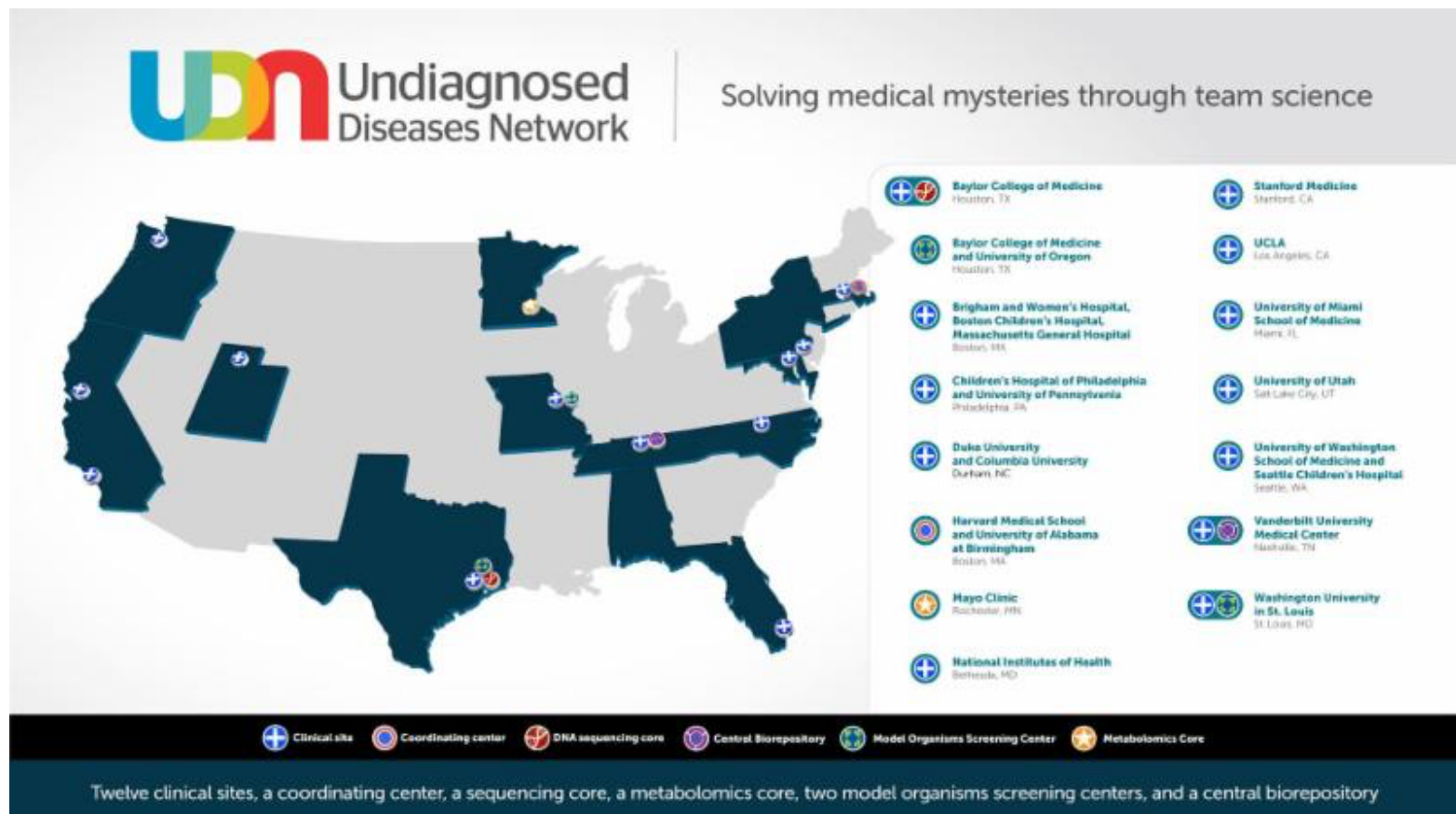
## Mountain States Regional Genetics Network



## Save the Date February 14-15, 2019 State Team Meeting

MSRGN will have an in-person State Team meeting in Austin, TX on Feb 14-15, 2019 at the [Renaissance Austin Hotel](#) located at 9721 Arboretum Blvd, Austin, TX 78759. The meeting will provide each State Team the opportunity to network with other State Teams within MSRGN, and the opportunity to work on current projects face to face with their team members as well as get feedback/suggestions on their current projects from others.

## Facebook Post of the Month



From the [National Human Genome Research Institute](#):  
The National Institutes of Health (NIH) has awarded 16 four-year grants to academic and medical centers nationwide to begin the second phase of the Undiagnosed Diseases Network (UDN). The total investment planned for the UDN over the next four years will be



approximately \$100 million.

Five new clinical sites will join the existing six academic clinical sites at Baylor College of Medicine; Duke University Health System with Columbia University; Harvard Affiliate Hospitals; Stanford Medical Center; the University of California, Los Angeles; and Vanderbilt University Medical Center. Added to the NIH UDP from Phase I, the new network of 12 clinical sites will comprise Phase II of the UDN.

The five new clinical sites are:

University of Washington (Seattle). Principal Investigators: Gail Jarvik, M.D., Ph.D., and Katrina Dipple, M.D., Ph.D.

Children's Hospital of Philadelphia. Principal Investigators: Kathleen Sullivan, M.D., Ph.D., and Reed Pyeritz, M.D., Ph.D.

University of Miami. Principal Investigators: Mustafa Tekin, M.D., and Stephan Zuchner, M.D., Ph.D.

Washington University in St. Louis. Principal Investigator: Francis Sessions Cole, M.D.

University of Utah (Salt Lake City). Principal Investigator: Lorenzo Botto, M.D.

## 2018 Genetics Summit Slides

The slides from the presentation at the 2018 MSRGN Genetics Summit can be found [here](#).

In addition, plans are underway for the 2019 MSRGN Genetics Summit. We would love to hear from you about your ideas for speakers, topics, workshops etc.

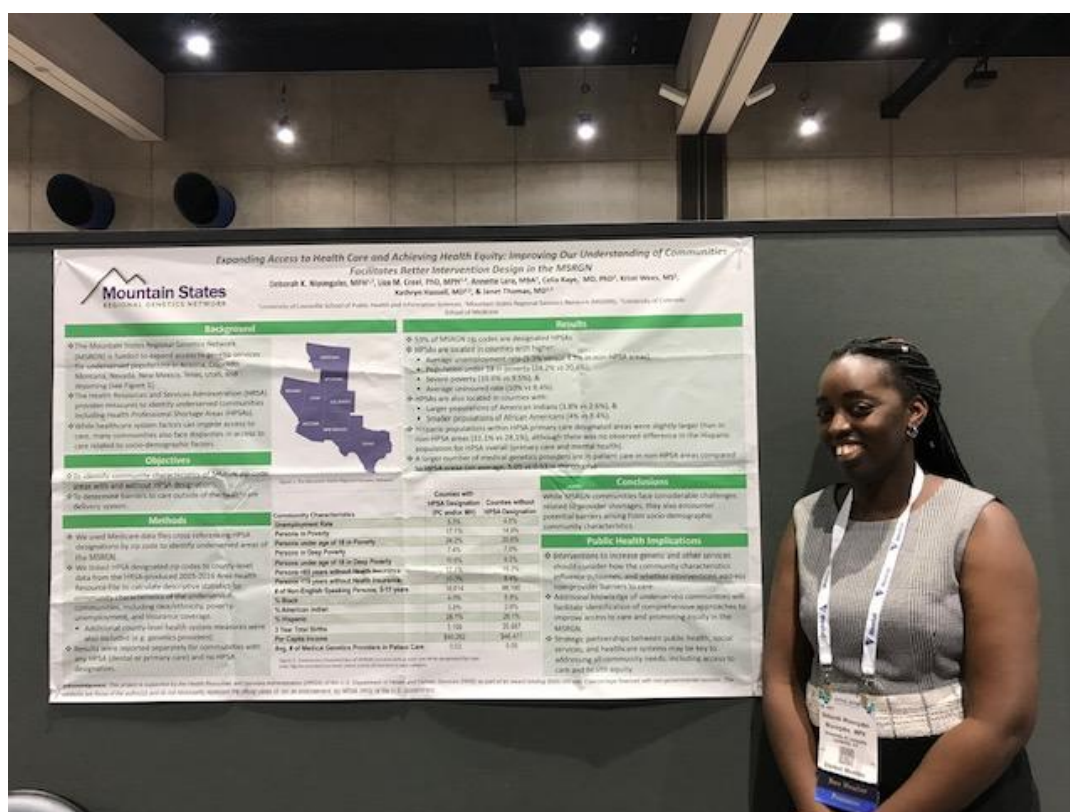
Please email your suggestions to [Annette Lara](#).

## Calling all Genetic Professionals

In September and October, MSRGN followers on Facebook submitted the top genetic questions they would like to learn more about. MSRGN is planning to offer answers to these questions through a Facebook live (5 to 7-minute video). If you are interested in assisting with answering one or more of these consumer questions about genetics, please email [Kristi Wees](#). Don't worry if you are a bit camera shy or nervous about going "live", we have the ability to pre-record!

## MSRGN Poster Presentation at American Public Health Association's (APHA) Annual Meeting

Deborah Niyongabo, Graduate Research Assistant, working on the MSRGN Evaluation team with Dr. Liza Creel, presented a poster at the APHA Annual Meeting on November 13, 2018. The title of her poster was: "Expanding Access to Health Care and Achieving Health Equity: Improving Our Understanding of Communities Facilitates Better Intervention Design in the Mountain States Regional Genetics Network." The poster illustrated how MSRGN communities face considerable challenges related to provider shortages and socio-demographic community characteristics.



(Deborah Niyongabo at APHA Annual Meeting in San Diego, CA)

## FOLLOW MSRGN ON TWITTER

MSRGN is now on Twitter. Please follow us [@GeneticMtnState](https://twitter.com/GeneticMtnState)

Warm regards,

Kathryn Hassell, MD  
Co-Project Director

Janet Thomas, MD  
Co-Project Director

### MSGRC staff contact information:

Kathryn Hassell, MD, Co-Project Director

[Kathryn.Hassell@ucdenver.edu](mailto:Kathryn.Hassell@ucdenver.edu)

Janet Thomas, MD, Co-Project Director

[Janet.Thomas@ucdenver.edu](mailto:Janet.Thomas@ucdenver.edu)

Annette Lara, Project Manager

[alara@mountainstatesgenetics.org](mailto:alara@mountainstatesgenetics.org)

Joyce Hooker, Community and Public Health Outreach Coordinator

[dnjhooker@msn.com](mailto:dnjhooker@msn.com)

Kristi Wees, Consumer Engagement Director & Social Media Coordinator

[kwees@mountainstatesgenetics.org](mailto:kwees@mountainstatesgenetics.org)

Liza Creel, PhD, Evaluator

[Liza.Creel@louisville.edu](mailto:Liza.Creel@louisville.edu)

Celia Kaye, MD, PhD, Genetics Services & Systems Consultant

[Celia.Kaye@ucdenver.edu](mailto:Celia.Kaye@ucdenver.edu)

**THI staff contact information:**

Ankit Sanghavi, Project Administrator

[asanghavi@texashealthinstitute.org](mailto:asanghavi@texashealthinstitute.org)

Sherry Wilkie-Conway, Project Oversight

[swilkie@texashealthinstitute.org](mailto:swilkie@texashealthinstitute.org)

Stephanie Ondrias, Director of Events & Education

[sondrias@texashealthinstitute.org](mailto:sondrias@texashealthinstitute.org)

***HAVE YOU VISITED OUR  
Website:***

[www.MountainStatesGenetics.org](http://www.MountainStatesGenetics.org)

## **Acknowledgement**

This publication is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$600,000 with 0 percentage financed with non-governmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more information, please visit HRSA.gov.

