





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

May 2019

Join Our List.

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Dear Friends and Colleagues,

We received notification in April that MSRGN has received full funding from Health Resource and Service Administration (HRSA) for 6/1/2019- 5/31/2020 grant cycle, the third year of our cooperative agreement. Our team is working on finalizing the agenda for the 2019 Genetics Summit scheduled for September 23-25 in Albuquerque, New Mexico

National Coordinating Center (NCC) Quality Improvement (QI) Meeting

Three of our MSRGN management team, Janet, Annette and Deborah, attended the NCC QI meeting in Denver, CO, on May 2-3, 2019. Discussions around identifying meaningful measures for the QI projects the regions are pursuing took place during this meeting. MSRGN is using QI methodologies to effectively reach as many people as possible with our Facebook Live events, which feature experts answering common questions about genetics asked by patients, families, and the community at large.



2019 Family Voices Leadership Conference

The Family Voices, Leadership Conference took place in Washington, DC, on May 8th-10th. Participants discussed strategy and resources to improve support to families of children and youth with special healthcare needs (CYSHCN). Representatives from Health Resources and Service Administration (HRSA), American Academy of Pediatrics (AAP), Association of Maternal and Child Health Programs (AMCHP), Got Transition, The Catalyst Center, and more addressed the group and shared possibilities to partner with family led organizations.

Kristi Wees, Consumer Engagement Director & Social Media Coordinator for MSRGN presented a breakout session: Consumer Engagement in a Virtual World by highlighting some of MSRGN's virtual and in-person consumer engagement initiatives.

Three members from our Genetic Ambassador's group and members of the MSRGN State Teams received a scholarship to attend the conference: Jamie Stefanski, Colorado State Team; Allysa Seymour, New Mexico State Team; Jenn Banna, Montana State Team.

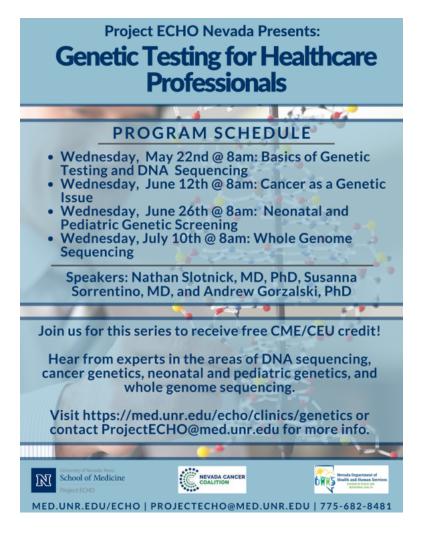


(Kristi Wees, Allysa Seymour, Jenn Banna, and Jamie Stefanski)

State Team Spotlight: Nevada

The Nevada State Team has partnered with Project ECHO Nevada, the Nevada Cancer Coalition and the Nevada State Public Health Lab in offering a four-part genetics educational series. This series will feature a range of topics including basics of genetics

testing, cancer genetics, pediatric genetic screening, and whole genome sequencing. The first session will occur on Wednesday, May 22nd at 8 am PDT. Nathan Slotnick, MD, PhD will lecture on the Basics of Genetic Testing and DNA Sequencing. The Nevada State Team was instrumental in coordinating the June 26th session, featuring Dr. Sorrentino, speaking on Neonatal and Pediatric Genetics. For registration information click here.



Mark your calendar for the 2019 Genetics Summit September 23-25, 2019



Mark your calendar now for this event! Many more details are in the works and will be forthcoming. MSRGN 2019 Genetics Summit will be in Albuquerque, NM. The Exhibitor application can be found here, if you know of any companies or organizations who would like to participate as an exhibitor.

FOLLOW MSRGN ON TWITTER

MSRGN is now on Twitter. Please follow us @GeneticMtnState

Email Communications from MSRGN

MSRGN is in the process of updating our contact list. If you would like to update your email preference or do not wish to receive communications from MSRGN, please email Annette Lara.

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

Janet Thomas, MD, Co-Project Director

Janet.Thomas@ucdenver.edu

Annette Lara, Project Manager

alara@mountainstatesgenetics.org

Joyce Hooker, Community and Public Health Outreach Coordinator

dnjhooker@msn.com

Kristi Wees, Consumer Engagement Director & Social Media Coordinator

kwees@mountainstatesgenetics.org

Liza Creel, PhD, Evaluator

Liza.Creel@louisville.edu

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

Celia.Kaye@ucdenver.edu

THI staff contact information:

Ankit Sanghavi, Project Administrator

asanghavi@texashealthinstitute.org

Sherry Wilkie-Conway, Project Oversight

swilkie@texashealthinstitute.org

Stephanie Ondrias, Director of Convenings & Education

sondrias@texashealthinstitute.org

Website:
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.

