



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

August 2018

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Dear Friends and Colleagues,

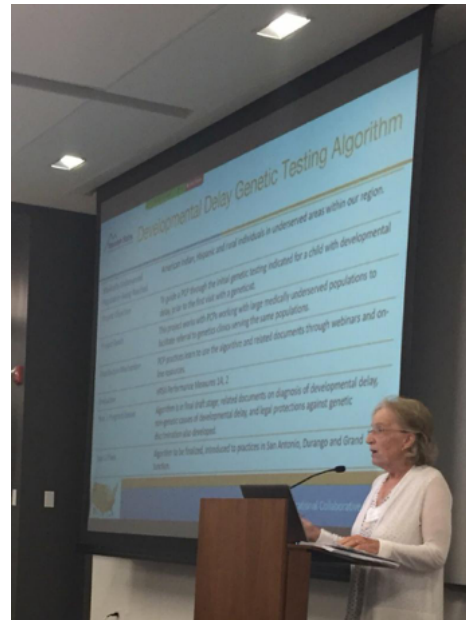
The heat of the summer is upon many of the MSRGN States. Our State Teams are busy working on their projects and the MSRGN planning team is working hard on getting the word out about the upcoming Genetics Summit. We would love your help in spreading the word!

MSRGN Participates in Project Director/Project Manager Annual Meeting

Kathryn Hassell, MD, MSRGN Co-Project Director; Celia Kaye, MD, MSRGN Genetic Services and Systems Consultant; Annette Lara, MSRGN Project Manager attended the PD/PM annual meeting in Washington, D.C. on August 8th and 9th. Each of the seven regional genetics networks presented on the underserved populations they are serving in their region, and gave an overview of the educational work conducted in their region for the first year of the grant cycle. This overview gave the regions an opportunity to share resources to prevent duplication of efforts. The regions also shared highlights of telegenetics implementation for year one and highlights for year two implementations. The regions discussed the challenges in data collection and evaluation of year one review and expressed their concerns on items that should be considered in the future.

The last day of the meeting focused on the Continuous Quality Improvement (CQI) Project Planning tool. Once the regions identified their root cause the tool will guide them through considerations that will assist them in identifying and planning a CQI project that

is small enough in scope to provide data quickly to test an initial concept. The initial CQI test is used to identify what works prior to implementing any changes to minimize cost and time.



(Celia Kaye, MD, PhD)

**Register today for the 2018 Genetics Summit
Limited Spaces Available**



When: Oct 2-3, 2018

Where: [Courtyard San Antonio Riverwalk](#)

Registration fees: \$75 for CE's (CME, CNE, SW, or Genetic Counselors)
\$50 non CE's

Registration: Online [here](#)

Agenda: [here](#)

Listed below are two sessions that will be offered at the **Summit:**

Rapid Genome Wide Sequencing in the NICU Uncovers a High Burden of Genetic

Disease- Speaker: David Dimmock, MD

This presentation will focus on cross-sectional data describing the incidence of genetic disease leading to the NICU admission at a single quaternary center. It will also provide parental & clinician perceptions of the utility of genome wide sequencing

Do You Want Fries With That? The Pros & Cons of Direct to Consumer (DTC) Genetic Testing- Speaker: Matthew Taylor, MD

This session will map some of the history of DTC testing & will explore current concepts, deliverable, & controversies in the field.

State Team Spotlight: Texas

The Texas State Team will be an exhibitor at the [Texas Pediatric Conference](#) in San Antonio, TX on Sept 6th and 7th. The team has developed a survey that will ask primary care physicians their experience in referring patients to genetic testing and how many genetic tests have they successfully obtained for their patients. As an incentive for those who complete the survey they will be entered into a raffle to win one of the four \$25 gift cards or a MSRGN t-shirt.

IHS Clinical Rounds: Nutritional Management of Genetic Disorders

Melissa Sailer, MS, RD, CNSC will be presenting on Nutritional Management of Genetic Disorders that will identify macronutrients involved in inborn errors of metabolism and goals of nutrition therapy, along with all nutritional considerations. Basic dietary treatment and intervention will be described for disorders of amino acid, organic acid, urea cycle, carbohydrate (galactose and glycogen) and fat (long-chain and very-long chain fatty acid) metabolism. This presentation will also provide an in-depth description of a galactose restricted diet along with an amino acid restricted diet and the importance of medical food, low protein food, whole protein foods and nutritional supplements

The webinar is scheduled for September 27th from 2pm-3pm CST. Information on how to register for this webinar can be found on the MSRGN website on this [link](#).

ECHO LITE Recording

For those of you who missed the Colorado ECHO on June 20th, the recording can be found on the MSRGN website on this [link](#).

This activity introduced participants to the Mountain States Regional Genetics Network with the goal of making genetic services more accessible to patients, families and clinicians through online learning and consultation. This session covered some new developments in genetic diagnosis and treatment, and participants had the opportunity to shape the content of future sessions in terms of topics and presentation of case scenarios.

Facebook Post of the Month

Check out this resource from the [Catalyst Center](#) on [#financialhardships](#) for families with Children and Youth with Special Health Care Needs ([#CYSHCN](#))

To see the entire resource, click [here](#).



FINANCIAL HARDSHIP IN FAMILIES RAISING CYSHCN

Inadequate insurance coverage and financing results in significant financial hardship for many families raising children and youth with special health care needs¹ (CYSHCN).



CYSHCN

Most CYSHCN have insurance, but having health insurance does not necessarily mean the coverage is adequate or affordable. Being insured is only part of the story. Many families make difficult sacrifices to help ensure adequate care for their CYSHCN.



FAMILIES



Inadequate health care coverage is a serious problem for a large percentage of families raising CYSHCN. Not every service or support CYSHCN need is paid for by insurance and as a result, families often incur large out-of-pocket (OOP) costs, resulting in financial hardship and medical debt.²

FOLLOW MSRGN ON TWITTER

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

Funding Opportunity for Healthy Tomorrows Partnership for Children Program (HTPCP)

We are pleased to announce Health Resources and Services Administration's (HRSA's) recent release of their funding opportunity for the Healthy Tomorrow Partnership for Children Program (HTPCP). [The full announcement can be found on Grants.gov: \(HSA-19-055\).](https://www.grants.gov/web/grants/listopportunities.html?term=HSA-19-055)

The purpose of this program is to support community-based services aimed at improving the health status of children, adolescents, and families in rural and other underserved communities by increasing their access to health services. This program supports the Health Resources and Services' (HRSA's) goals to improve access to quality health care and services, build healthy communities, and improve health equity. Community-based programs and evidence-based models of care that build on existing community resources will be implemented and evaluated to demonstrate program impact. This program supports collaboration between local pediatric providers and community leaders in an effort to provide quality health care and preventive health services to children, adolescents, and families in rural and other underserved communities. HTPCP funding supports projects that provide clinical or public health services, and does not support research projects. HTPCP applications MUST represent either a new initiative (i.e., project that was not previously in existence) within the community or an innovative new component that builds upon an existing community-based program or initiative. [Click here to read more.](#)

Consumer Engagement Director

On June 1, Kristi Wees' M.S. Chem, role with MSRGN was expanded to: Consumer Engagement Director and Social Media Coordinator. In this new role, Kristi will work with the management team, state teams and MSRGN members to identify opportunities to further engage consumers in the work and mission of Mountain States Regional Genetics

Network. She will also actively engage consumers in our eight state region, connecting them with projects, resources, and events in the MSRGN region. It has been a long-standing tradition in the region to include consumer representation and perspective at all levels of the network. It is this very tenet that led Kristi to find MSGRC (the collaborative at the time) through a web search when she was looking for genetic answers for her daughter's health struggles over 7 years ago. Kristi will be moderating our consumer panel at the Genetics Summit and also teaching a consumer training course on the last day of the summit, called "Serving on Groups". If you know of consumers who would like to get involved with MSRGN, please connect them with Kristi [here](#).

Submission Requested



We are always looking for NEWS from our members! That is you! If you have an event, webinar, state team update, recent publication, promotion or other "genetics" news you think that our Mountain States region would benefit from knowing about, please send it to us! Our newsletter deadline is the 10th of each month, so please send submissions to our: Project Manager, Annette Lara alara@mountainstatesgenetics.org

Warm regards,

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**HAVE YOU VISITED OUR NEW
Website:**

www.MountainStatesGenetics.org

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