# Mountain States REGIONAL GENETICS NETWORK

**JULY 2020** 

# MSRGN Project Directors' Message



New Projects
Manager
Our new grant cycle is in full swing! Please join us in welcoming, Kristi Wees, as she transitions into the role of our new Projects Manager. Kristi has been involved with the network and the collaborative since 2011 when she found

the Mountain States Genetics website during a Google search, trying to find answers for her daughter's health. She picked up the phone and called the then project manager (Liza Creel at the time, now the evaluator of our grant), and the rest is history. Kristi has worn a number of hats from social media coordinator to director of consumer engagement with the network and has spent years helping families advocate medically for their children. You can read more about Kristi here, along with the biographies of the rest of our management team for this grant cycle. Please reach out to Kristi by email when and if you have any questions, concerns, ideas, or want to be more involved in the exciting work MSRGN has planned for the next four year.

## MSRGN July Highlights:

 MSRGN had our grant kick-off call with our grant officer on July 9, 2020. If you

# MSRGN's State Team Overview Document

Read All About Our State Teams

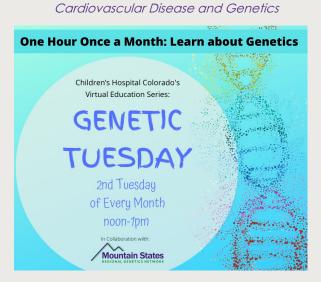
In the 2017-2020 grant cycle, the state team model was implemented in the Mountain States region as part of the infrastructure for improving access to aenetics care. Gone are the days of workgroups and committees for MSRGN. Over the last three years, with so many of you helping to refine this model, we have worked to improve the state team approach in our region. We are excited to let you know some of the other regional genetics networks across the country have decided to implement the state team model during this new cycle. This document was created and recently updated with state team projects to give an overview of the state teams that are so integral to the work we do in MSRGN.

would like to read the grant abstract for the 2020-2024 grant cycle, you can download it here.

- Our Management team met for a half day zoom call retreat: CAMP MSRGN on July 29, 2020 to further develop a number of new initiatives for this new grant cycle.
- State Team calls and the Genetic Ambassador calls resumed in July, welcoming many new members and attendees.

### Save the Date: Virtual Education Series August 11, 2020

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The Colorado Team in conjunction with Children's Hospital of Colorado is hosting Genetic Tuesday from noon-1pm MT on Tuesday August 11, 2020. The topic will be:

#### **Matters of the Heart:**

#### Cardiovascular Disease and Genetics

For more information and registration, click here.

Read State Team
Overview Here

#### **Mountain States**

What to do when you suspect Ehlers=Danios Syndrome ((EDS))

- a practical guide for primary care and pediatricians

## NEW Algorithm for: Ehlers-Danlos Syndrome (EDS)

for Primary Care and Pediatricians

As many of you are familiar, MSRGN launched our first Algorithm in 2018 for Developmental Delays. These algorithms are aimed at helping pediatricians and primary care physicians with the preliminary work-up for suspected genetic conditions. In May, with the help of Dr. Abe Elias' (MT) leadership and a wonderful workgroup, MSRGN launched the second algorithm for when a provider suspects Ehlers-Danlos Syndrome (EDS) in a child. Click the button below to read more and share this link with your colleagues.

> View EDS Algorithm Here

Would you like to be more involved in this new grant cycle? Please, <u>Contact Us!</u>



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