



# Mountain States

## REGIONAL GENETICS NETWORK

June 2021

## MSRGN Project Directors' Message



MSRGN



OUR YOUNGEST  
TEAM MEMBER



ROCKS!

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

On June 1, 2021, MSRGN began the second year of our current (2020-2024) grant cycle. We will be referring to this year as "Year 5" for evaluation purposes since it is a continuation of our last 3 year grant cycle (3+2=5!). We are excited to continue the work we have been doing over the last 4 years and have some great plans for the 2021-2022 grant year! Our Management team met for a Virtual Retreat (our theme was: MSRGN Rocks!) early in June and discussed details and improvements for Year 5 including:

- Improving support for the MSRGN State Teams through project and funding processes.
- Streamlining of the Time 4 Genetics Clinic selection process.
- Resources for interpretation and translation of materials into other languages.
- An evaluation review of MSRGN programs and "Pebbles and Buckets" (more coming on this soon).
- Journey mapping and helping families and states identify boulders and barriers and designing programs to specifically bridge or blast those barriers.
- Check out our team building craft activity above: rock painting and Congratulations to Maddie who won the Rock, Paper, Scissors Tournament!

"The person who moves a mountain begins by carrying away small stones."



## Welcome Cody to a new role!

Cody Price, our administrative assistant, will be taking on additional roles and responsibilities as MSRGN's new State Team Coordinator for the upcoming grant year. Please join us in congratulating him on this new role and supporting him as he takes on these additional responsibilities and becomes the primary point of first contact for the MSRGN state teams. Cody will attend all state team calls and be the MSRGN staff available on those calls for questions and MSRGN updates. Though Kristi will not be regularly attending the monthly state team calls, she will pop-on every now and then as needed. If you need to contact Cody you can email him [here](#), and you can reach Kristi [here](#).

**RED FLAGS 4 GENETICS**

Do you have concerns about your child? Below are red flags or warning signs and symptoms that were self-reported by families whose child went on to receive a genetic diagnosis. 89% of reported red flags were noted before 4 years of age.

- Developmental Delay**
  - Physical/motor delay (not rolling, sitting, crawling or walking)
  - Speech not babbling or responding to name
  - Adaptive (coordination of hands and fingers)
  - Cognitive (unable to or not interested in play)
  - Social/emotional (difficulty interacting with others, not smiling)
  - Loss of any milestone (regression)
- Physical Features**
  - Extra fingers or toes
  - Large/small head size (macrocephaly/microcephaly)
  - Short/tall height (stature)
  - Cleft palate
  - Facial feature differences (small chin, wide forehead)
  - Frequent joint dislocations (hip dysplasia)
  - Spinal deformities (scoliosis)
- Feeding Issues**
  - Difficulty swallowing
  - Struggles with breastfeeding
  - Poor appetite
  - Poor latch
  - Feeding tube dependent
  - Vomiting
  - Slugging on food
- Behavior**
  - Autism Spectrum Disorder (ASD)
  - Repetitive movements
  - Constantly upset or crying
  - Lack of eye contact
  - ADHD/impulsive or hyperactive behavior
  - Easy distractible
  - High pitched cry/hoarse voice
- Failure To Thrive**
  - Slow growth
  - Slow weight gain
  - Not thriving
  - Fatigues quickly when active
  - Weight or rate of weight gain being much lower than that of other children
- Strength & Tone**
  - Flabby or low muscle tone (hypotonia)
  - Stiff or high muscle tone (hypertonia)
  - Baby not attempting to roll over
  - Can't hold head up when on tummy
  - Muscle weakness
  - Body is floppy
  - Inability to lift or control head (head lag)

**Other Red Flags**

- Seizures
- Sleep concerns
- Fatigue
- Lethargy
- Hearing/vision concerns
- Immune issues
- Headaches/migraines
- Neurological concerns
- Pulmonary/cardiac concerns
- GI issues (reflux/bowel concerns)
- Drinking

If your child is exhibiting any "red flag" on this page, please talk to your child's pediatrician or primary care physician. For more resources and help having that conversation, go to: [www.mountstatongenetics.org/redflags](http://www.mountstatongenetics.org/redflags)

MSRGN Genetic Ambassador's Project Launch:

## Red Flags For Genetics Handout

for Families and Providers

MSRGN, in partnership with all the families who contributed to the red flags survey and those who serve as our [Genetic Ambassadors](#), is pleased to launch this [Red Flags 4 Genetics Handout](#) for families and practitioners alike. It is our hope that this document will aid in the conversation between families and their trusted providers about concerns they have about their child that may need genetic follow-up.

Download the Red Flags 4 Genetics PDF [here!](#)



Continuing education credit for multiple disciplines will be provided for this event

Texas Department of State Health Services

## 2021 Texas Genetics Conference

Saturday, July 10, 2021

LIVE / FREE / ONLINE

Read more about it and [Register Here](#)

More Information for the Texas Genetics Conference



### REMINDER:

State Team calls resume in JULY.

### State team members:

Be on the lookout for a new calendar invite for your state team call!

If you have not received an invite

## Quarterly Genetic Ambassador Call: July 2021

July 27, 2021  
1pm ET/noon CT/  
11AM MT/10 AM PT

Please contact Kristi if you have not received the invite or if you were interested in learning more about our [MSRGN Genetic Ambassador group](#).



The MSRGN Genetics Summit 2021: Connecting the Dots Planning Committee has been busy inviting speakers to our 2-day virtual summit on

### November 9-10, 2021

Please hold these dates on your calendar for this 2-day VIRTUAL event.

We will start at:

**8:30 PT, 9:30 MT, 10:30 CT, 11:30 ET**  
and end at:

**1:30 PT, 2:30 MT, 3:30 CT, 4:30 ET**  
with breaks and lunch.

for July, please contact Cody.

## Acknowledgement of Funding

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 nongovernmental 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](http://HRSA.gov).

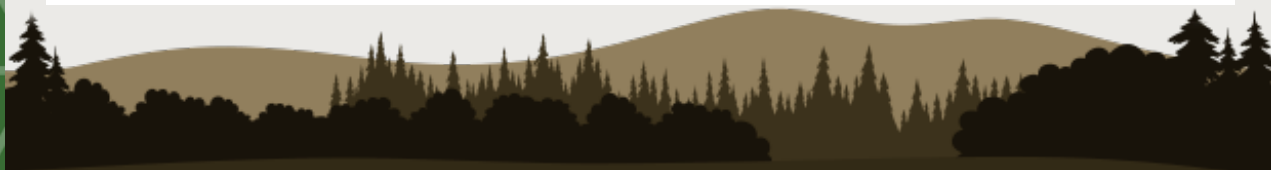
## The MSRGN Management Team

*MSRGN staff contact information: (click on name for email address)*

- Kathryn Hassell, MD, Co-Project Director
- Janet Thomas, MD, Co-Project Director
- Kristi Wees, Projects Manager
- Liza Creel, PhD, Evaluator
- Cody Price, State Team Coordinator

*THI staff contact information: (click on name for email address)*

- Ankit Sanghavi, Project Administrator
- Sherry Wilkie-Conway, Project Oversight
- Stephanie Ondrias, Director of Convenings & Education



Mountain States Regional Genetics Network  
512-279-3910

[www.MountainStatesGenetics.org](http://www.MountainStatesGenetics.org)  
[View as Webpage](#)

Connect with us

