



January 2023

## MSRGN Project Directors' Message

### Here's to 2023!

A new year is an opportunity to reflect on the past year and look forward to the 12 months of the new year ahead of us! In December, the MSRGN management team did just that with a virtual retreat. We reflected on the first 7 months of our Year 6 grant year and solidified plans for the last 5 months of this grant year while also looking forward to Year 7. Over the next 4 weeks the MSRGN management team is writing our non-competitive continuation (NCC) report for HRSA which recaps all the work the entire region has done and what our plans are for future funding.

We want to take a moment to THANK ALL of you for your support, leadership, work, collaboration and partnership in our region to help improve access to genetics care in the Mountain States and beyond!

Happy New Year-  
*from the MSRGN Management team*

Genetics Pop-Up:  
Rare Disease Day 2023

# GENETICS POP-UP

Featuring:  
**Rare Disease Day**

*Raise Awareness and  
Generate Change*

• FEBRUARY 21, 2023 •

**2pm ET • 1pm CT  
noon MT • 11am PT**

This event 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 \$600,000.00 with 0 percent 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.

Join us for the February Genetics Pop-Up!

*In honor of Rare Disease Day 2023*

**February 21, 2023**  
**2pm ET • 1pm CT • noon MT • 11am PT**

Join us to learn more about genetics! Experience a safe arena to ask questions, learn about resources, and connect with others who have explored genetics for their own loved ones.

At this virtual event on February 21, 2023 MSRGN will be talking about  
Rare Disease Day!

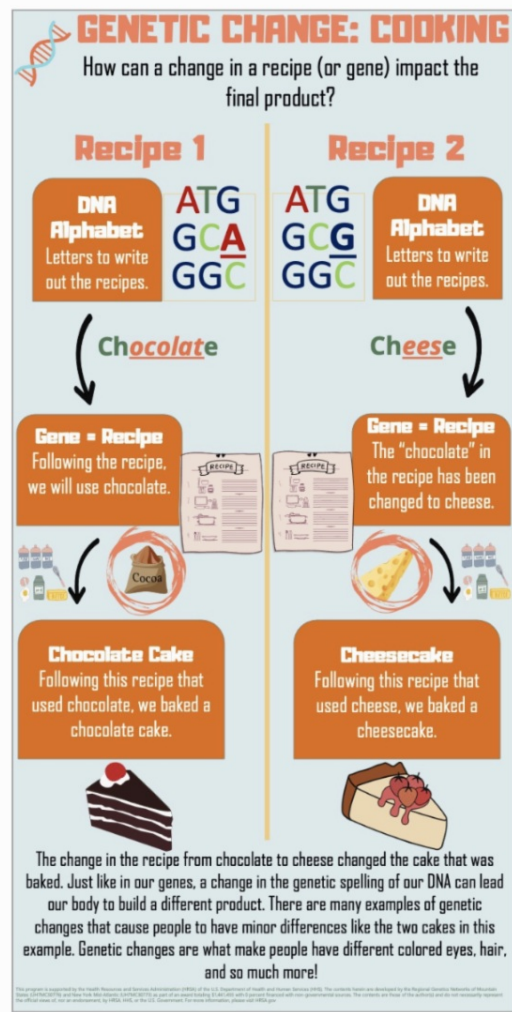
You won't want to miss learning about Rare Disease Day  
from those in the genetics community.

REGISTER to join us [here](#).

A PDF Flyer to share [here](#).

Graphic to share on social media [here](#).

**Register for the Genetics Pop-Up  
Here**



## MSRGN and NYMAC collaborate to create Genetic "Cake" Infographics

Mountain States Regional Genetics Network (MSRGN) in collaboration with The New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC) is pleased to share 2 new infographic resources:

The Genetic Recipe: this infographic presents an analogy that helps in the understanding of genetic terms like DNA, gene, chromosome and genome as related to a recipe and baking a cake.

Genetic Change: this infographic presents a comparison analogy between baking a chocolate cake and a cheese cake and how a few letters being changed in the letters (DNA alphabet) used to write out the recipe (gene) can result in a change in the results (cake or genetic change).

To download these infographics please click on the images below or the titles above.

**Download new Infographics Here**



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## Welcome our newest Genetic Navigator for Wyoming!



Kala McWain is a mother of two from Casper, Wyoming. Her youngest son, Braxton, was diagnosed with phenylketonuria (PKU), a rare metabolic disorder, at only four days old. In the two years since his diagnosis, Kala has worked tirelessly to build public awareness of the disease and advocate for the needs of her son and others like him.

Kala can be reached at the Wyoming Genetic Navigator email address: [wyoinggenetic@gmail.com](mailto:wyoinggenetic@gmail.com)

Welcome and Connect with Kala  
here

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**NEW DISCOVERIES IN THE  
EVOLVING WORLD OF GENETICS:  
DIAGNOSIS AND TREATMENT OF  
CEREBRAL PALSY**



Did you miss the  
Time 4 Genetics  
Cerebral Palsy Webinar?

Dr. Michael Kruer from Phoenix Children's Hospital presented a webinar on 1/10/23 on the topic of:  
New Discoveries in the Evolving World of Genetics: Diagnosis and Treatment of Cerebral Palsy.

The recording is available below for viewing and for no-cost CME/CEU enduring credits:

#### Time 4 Genetics Cerebral Palsy Webinar Recording

A resource for those interested on updates in the world of Newborn Screening:  
**APHL's 2022 Newborn Screening Symposium Recordings**

[View Recordings Here](#)



#### Grant Year 5: June 2021 to May 2022 Data

Since 2017, the RGNs, National Coordinating Center (NCC), and Family Center have submitted data on an annual basis to NCC on five Performance Measures to measure how well we are improving access to genetic services for underserved populations. In December 2022, NCC added data from the previous funding year (Year 5)- June 2021 to May 2022- on their website dashboard.

#### Recap:

During this time period, the RGNs connected 1,370 people to genetic services, supported 108 clinics in offering telegenetics services, and served 19,140 patients as a result. The RGNs, NCC, and the Family Center held 170 educational events which reached 4,111 providers and 907 individuals and families with, or at risk for, genetic conditions.

Explore this data and more by visiting the "Our Impact" webpage on the NCC's Website.

View "Our Impact" Data  
here

## State Team Accomplishments & Momentum



Each month we will be highlighting the projects and accomplishments of our state teams.  
This month we are highlighting:

## ARIZONA

Click [here](#) (or on the image above) to take a closer look at the Arizona State Team's accomplishments infographic.

This is a graphical summary of some highlights from Years 4 & 5 of this grant cycle and also what momentum the team is building on for year 6! To learn more about the Arizona State Team check out their updated team page [here](#).

If you live in the mountain states and are interested in getting involved in the state team in the state where you live, please reach out to our state teams coordinator, [Jamie Stefanski](#) or fill out this form [here](#) and note your interest in the **state teams** in the "Why are you interested in connecting with MSRGN?" box.

## Acknowledgement of Funding

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## The MSRGN Management Team

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- Ankit Sanghavi, Project Administrator
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[View as Webpage](#)

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