



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

February/March 2020

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Dear Friends and Colleagues,

As the clocks spring forward in most of our region (except states like Arizona!), we are looking forward to the warmer spring weather and the wildflowers that will soon bloom. Almost three years ago (April 2017), our region met in Salt Lake City, UT for our final annual meeting of the regional collaborative grant cycle with a theme of 'Seeds of Sustainability: Cultivating Genetics Across the Region' and a tag line: 'Bloom Where You Are Planted'. As we prepare to wrap up the last 3 months of this current regional genetics network grant cycle, we want to thank all of you for all the seeds you have planted and for truly blooming where you are planted! Our members, our state teams, our genetic ambassadors and colleagues have shared the wealth of their genetics information/resources and expanded access to care right in our own communities and in our Mountain States Region. We are still awaiting word from HRSA on the plans for the continuation of this work!

We hope this newsletter finds you staying safe and healthy during this time of COVID19 concerns and precautions. Our thoughts are with you all for safety and health for you and your families.

Genetic Awareness Weeks

Mark your calendar!

March 17-21 is [Medical Genetics Awareness](#) week.

and

April 25th is [National DNA Day](#)

and
May 26-29 is Public Health Genetics Week (more info coming soon!)

Rare Disease Day, Week and Month in the Mountain States

Genetics Pop-Ups 2020

MSRGN honored RARE Disease Day by holding Genetic Pop-ups in all eight states of our region. Check out some of the photos from pop-ups that have already taken place! For more information on the Genetic Pop-Ups click [here](#). A HUGE thank you to all our Genetic Ambassadors who spearheaded these events:

Arizona:

Melinda Burnworth
Becki Coleman
Kathy Levandowski

Colorado:

Heather Schichtel
Brittany Parke
Jamie Stefanski
Maria Castillo

Montana:

Jenn Banna

Nevada:

Amy Holly
Mary Meeker

New Mexico:

Elvira Dennison/Josey Foo

Texas:

Alysian Thomas

Utah:

Gina Money

Wyoming:

Kenneth Allen
Melody Ruppel



University of Arizona, Tucson



Missoula, Montana



Aurora, Colorado



Farmington, New Mexico



Tucson, Arizona



Reno, Nevada



Midvale, Utah

COVID19: Emergency Preparedness Resource

[The National Coordinating Center](#) (NCC) has just released this [clickable infographic](#) with links to resources for genetic providers and patients during this COVID19 emergency response. Here is a link to our [facebook post](#) that can be shared. Please let others know about this helpful resource.

EMERGENCY PREPAREDNESS RESOURCES FOR GENETIC PROVIDERS AND PATIENTS

Click below for resources developed by the RGNs, NCC, TRCs, CDC, and Family Voices.



NYMAC EMERGENCY PREPAREDNESS CARDS

Condition-specific printable cards to be carried in case of emergency.



SERN EMERGENCY PREPAREDNESS TOOLKIT

Condition-specific list of supplies needed in case of emergency, as well as a general list of basic emergency preparedness supplies.



NCC "FIND A GENETICS CLINIC" DIRECTORY

Find a genetics clinic throughout the United States by visiting clinics.acmg.net.



CDC COMMUNITY ACTIVITY CALL COVID-19

On March 12, CDC held a call for clinicians about how to care for children and pregnant woman.



NCTRC TELEHEALTH AND COVID-19

The National Consortium of Telehealth Resource Centers (NCTRC) will be holding a webinar on March 19th about telehealth and COVID-19.



CDC COVID-19 FACT SHEETS

Printable materials about COVID-19 can be found from the CDC.



CDC COVID-19 PREGNANCY FACT SHEET

Information about COVID-19 for pregnant woman.



FAMILY VOICES COVID-19

Family Voices has a webpage dedicated to resources for families.

As resources are developed that are relevant to the genetics community, NCC will add them to ReRe, available at nccrcg.org/resources.

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State Team Spotlight: Wyoming

The Wyoming team has been busy preparing for their Genetics Pop-Ups this month, with two held near rare disease day (Sheridan and Riverton). The genetic pop-up in Riverton was coordinated with genetic ambassador and recent genetic summit scholarship recipient, Melody Ruppel, with the support of state team lead, Carleigh Soule (pictured below). Recently, the Wyoming Department of Health has expanded their telegenetics outreach and services to the Riverton area, so the pop-up offered an opportunity to bring genetic resources to that community.



Newborn Screening Education for Families

From Expecting Health:

[Navigate Newborn Screening](#) is a free learning opportunity that provides families with timely newborn screening information. [Navigate Newborn Screening](#) builds the capacity of families, new and expecting parents for storytelling, advocacy, and information seeking in the newborn screening system. The module provides information and tools to understand and act on newborn screening results.

Some key facts:

- It's a free module.
- It takes 40-45 minutes to complete.
- Watch on your computer or phone - wherever you are.
- Play and pause the modules to learn on your own schedule.

Warm regards,

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