# Mountain States REGIONAL GENETICS NETWORK

February 2021

### MSRGN Project Directors' Message



#### We **HEART** Genetics!

Love is in the air and so is a cold blast of winter in our region! Our members and staff in Texas were getting Colorado-like temperatures and snow last week. Our thoughts are with them as many are struggling with broken water pipes, days without power, and for some, much worse conditions. Though February is a short month, it has been jam-packed with all things genetics here at MSRGN.

#### MSRGN February Highlights:

- We submitted our Non-Compete HRSA/NCC Progress Report for the first year of this new grant cycle.
- We received overall very positive feedback on our Virtual Winter Meeting. If you missed the meeting you can access the recordings and slides here.

# Red Flags and Explainer Video Surveys

- Calling all individuals and families living with genetic conditions- Please take and share this survey about the Red Flags for Genetic Conditions that you experienced on your journey.
- Available in English & Spanish
- Calling all Geneticists,
   Genetic Counselors,
   Primary Care Providers,
   Pediatricians, Nurses, Non-Genetic Specialists and
   anyone who talks to
   families about genetics in
   a clinical setting. We are
   making videos to explain
   genetic topics to families
   and need your input on
   the topics!
- Take the survey here.

Both Surveys will close March 20th.

Inclusion Workgroup

- We asked for your feedback through a survey on the format for our 2021 Genetics Summit. Thank you for your responses! We are exploring VIRTUAL options based on your feedback. Stay tuned for more details coming soon!
- Our <u>Genetic Pop-Ups</u> launched Feb 17th and are ongoing through March 10th. Join us for one virtually!
- Our <u>Genetic Navigator</u>
   <u>Application</u> (see below) is <u>OPEN</u>
   now and closing on March 1st. So
   far we have had 9 applications!
   This is a stipend-funded position
   (\$1000 for training) Please Apply
   <u>here</u>.



#### 2021 Genetic Pop-Ups for Rare Disease Day

Eight VIRTUAL Genetic Pop-Ups are underway in our region!
Join us for one of the Genetic Pop-Ups that fits your schedule!
It doesn't matter what state you live in since all genetic pop-ups are virtual this year!

Jamie's on 2/26 Emma's on 3/4 Hannah's on 3/4

# LAST CALL for Genetic Navigator Applications!

The MSRGN Genetic Navigator program is an initiative to help families navigate the genetic services system in their state of

## forming for the Family Center

The National Genetics Education and

Family Support Center (Family Center) is a core program of Expecting Health. The Family Center Workgroup on Inclusion (FCWI) is taking applications for 8-10 family representatives from around the U.S. and U.S. territories who will participate in a one year term. The FCWI is tasked with asking hard questions and having difficult conversations to identify inequities and barriers to inclusion so that we can address them and achieve a more inclusive and vibrant community. The FCWI's role is to support the Family Center in ensuring strong family-professional partnerships and that families are central to genetic health care delivery systems around the nation and U.S. Territories through the development of products, resources, and trainings.

#### **Time Commitment**

The FCWI meets via video conference call twice annually to discuss ongoing projects and relevant Family Center updates with additional opportunities to participate in relevant projects, if interested.

#### Compensation

FCWI members will be compensated \$35/hr.

Application due:

Wednesday, February 24th

**Apply Here** 



Rare Disease Day at the NIH

residence. There are 8 Genetic Navigator spots available. The genetics navigator role is a stipend-funded role (\$1000 paid at completion of training). Currently, this program is only open to individuals in the Mountain States Region States of Arizona, Colorado, Montana, Nevada, New Mexico, Texas, Utah, and Wyoming.

We have NOT had anyone apply yet from UTAH or NEW MEXICO.

Application Deadline March 1, 2021

Apply Here

Rare Disease Day at NIH will be held virtually on Monday, March 1, 2021, from 10:30 a.m. to 5:30 p.m. EST. This year's event will feature interactive panel discussions, rare stories through TED-style talks, and more. The event is free and open to the public, including patients, patient advocates, healthcare providers, researchers, trainees, students, industry representatives, and government employees.

Register Here

#### Save the Date!

May 24-28, 2021 ~Public Health Genetics Week~www.phgw.org



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