

March 2024

MSRGN Project Directors' Message



As March wraps up, we are entering our last 2 months of the Mountain States Regional Genetics Network grant.

Looking forward to APRILwe want to be sure that everyone has registered for our last virtual convening:

Sunsetting Mountain States
Celebrating the end of an era
April 11, 2024
(more details below)

Register **Here**We hope to see many of you on ZOOM on <u>April 11th!</u>

April 1st is the deadline for all our State Teams to expend their funds!

Also happening in <u>April</u> is NEW Genetic Navigator training with a focus on navigating with families with-in the genetics clinic. See the details below and share with any families who might be interested.

Thank you, the MSRGN Management team



Register here for
Sunsetting
Mountain States:
Celebrating the End of an Era!

virtual event to be held on:

**April 11th** 

from 2-4:30 ET/1-3:30 CT/ noon-2:30 MT/11am-1:30 PT

The first hour or so will be dedicated to hearing from our state teams about their projects and their sustainability plans.

The second hour or so will have a focus on celebrating our successes over the years as well as reminiscing and a bit of nostalgia as we reflect on nearly 40 years of regional genetics networks.

Please save the date and if you can join us please registerhere!

**Register Here** 



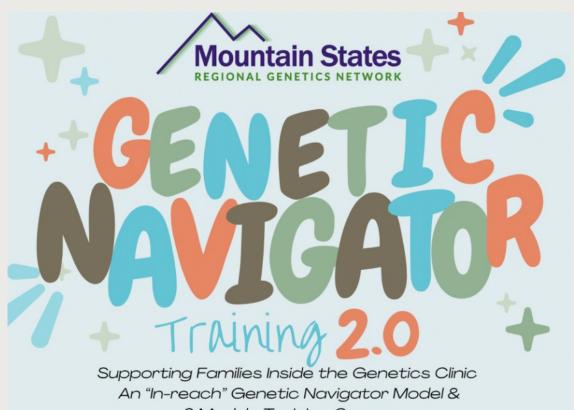
## March UPDATE

Thank you for helping spread the word to families about the NBS Listening Sessions!
Nineteen families from all 8 of the Mountain States, participated in 2 Listening Sessions in March.

This work in our region is part of a larger national initiative to identify a broad set of long-term outcomes for families as a result of NBS and develop a measure to assess family outcomes. In May, we will be sharing what family outcomes are important to families in the Mountain State Region with an Expert Advisory Council that RTI International is convening.

# STATE TEAM REMINDER:

April 1st is the deadline for all state team funds to be expended. Any funds that are not utilized by April 1st will be re-allocated to other MSRGN projects.



6 Module Training Course

In 2021, MSRGN implemented a Genetic Navigator (1.0) outreach initiative in all 8 of our states. Over the last 3 years the MSRGN genetic navigators have facilitated over 250 family connections in our region.

We have now developed a new Genetic Navigator training specifically for inside the genetics clinic or an "in-reach" (vs. outreach) program and we are calling this Genetic Navigators 2.0.

This new training consists of 6 modules and the training will be offered one time before MSRGN sunsets on 5/31/24.

The training is offered at no charge to the individual, however, funding is NOT available at this time to offer stipends for training or ongoing navigation activities.

#### Who:

MSRGN invites individuals\*\* who have experience navigating genetics for their own loved ones and who are now interested in helping other families, potentially inside a genetics clinic in their area, to register to join us for Genetic Navigator 2.0 Training.

### **Genetic Navigator 2.0 Training**

Supporting Families Inside the Genetics Clinic An "In-reach" Genetic Navigator Model & 6 Module Training Course

Dates and Times Training:

April 22: noon-1:30 ET April 23: 1pm-2:30 ET April 29: 1pm-2:30 ET

April 30: 1pm-2:30 ET

Registration: <u>here</u> PDF Flyer: <u>here</u>

\*\*If you are not a family member or individual who has navigated genetics for yourself or a loved one, but would like to attend the training, please email **Kristi Wees** for consideration as priority registration is reserved for those with lived genetic navigation experience.

**Register Here** 

#### 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.

### 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
- Mikayla Welch, Project 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



### $\underline{\mathsf{Update}\;\mathsf{Profile}\;|\mathsf{Constant}\;\mathsf{Contact}\;\mathsf{Data}\;\mathsf{Notice}}$

Sent bykwees@mountainstatesgenetics.orgpowered by

