

April 2022

MSRGN Project Directors' Message

April Showers (and Snow) have lots Springing up at MSRGN...

The MSRGN Management team has **GROWN** by TWO! Please join us in welcoming Jamie and Mekayla. More details about our new team members below.

Help our Genetic Summit Speaker/Topic suggestion list**BLOOM** with your suggestions for topics and speakers for the MSRGN Genetics Summit 2022 Virtual event to be held on November 9-10, 2022.

Our Genetic Ambassadors are PLANTING NEW SEEDS...

Do you know an individual or family that has a passion for genetics advocacy, awareness, education and leadership? Invite them to our MAY Genetic Ambassador meeting on May 19th!

Details below.

Our Time 4 Genetic Cohort just SPROUTED eleven new clinics for cohort #2 which are joining the 7 clinics from cohort #1 for the new topic of GENETIC TESTING for April through July. Check out the upcoming WEBINAR below on May 18th.

Stay tuned for some exciting CROSS-POLLINATING opportunities for Year 6 between the 8 states in our Mountain States Region



Welcome Mekayla! Projects Coordinator

We are thrilled to
have Mekayla returning to MSRGN
after serving as the MSRGN/THI
Intern through her graduate
program at Sam Houston State
University (SHSU) in Huntsville, TX. She
completed her master's degree in
Public Health in August
2021. Mekayla hopes to advance
her career in the realm of genetic
education. Mekayla's prior work
experience includes her role as a
Marketing and Events Coordinator
for the Office of the Vice President
for Student Affairs at SHSU.

We are excited to have Mekayla join our team as the Projects Coordinator for MSRGN.
She will be sharing her time between MSRGN and Texas Health Institute and started with MSRGN/THI on April 18th.

Click the button below to send a Welcome email to Mekayla

Email Mekayla



Welcome Jamie! State Teams Coordinator

We are thrilled to also welcome Jamie Stefanski to the MSRGN Team.

Jamie comes to the State Teams Coordinator Position with prior experience as a MSRGN Colorado State team member since 2018, a former Colorado state team co-lead and as the current Colorado Genetic Navigator. Jamie is a Physical Therapist, ABM NeuroMovement Practitioner, and a mother of two children with the rare genetic condition. She also serves on the Special Education Advisory Committee (SEAC) for her local school district and has hosted multiple MSRGN Genetic Pop-Ups, free NeuroMovement clinics, and other special needs events. Jamie and her family have lived in Colorado since 2017. Prior to moving to Colorado, she has navigated genetics in five other states, providing her with vast experience navigating the medical system, insurance system, special needs services, and medically complex and genetics worlds as a professional and parent.

We are excited to have Jamie join our team as the State Teams Coordinator for MSRGN. She will be primarily

serving our state teams as of April 11th.

Click the button below to send a Welcome email to Jamie

Email Jamie

Help us say Goodbye to Cody!

Cody will be wrapping up his last state team calls over the next few weeks and will be training Jamie and Mekayla on many of the tasks he will be handing over to them. We have been honored to have him as part of our MSRGN team and wish him the best in his new full-time health policy analyst role with THI.

Email Cody

SUGGEST A TOPIC! SUGGEST A SPEAKER!

for the MSRGN Genetics Summit 2022 November 9 & 10, 2022

The MSRGN management team has made the decision to offer our annual Genetics Summit as a virtual event for 2022.

Please Save The Dates: November 9 & 10, 2022

If you have ideas for topics or speakers or any topics from last year's Genetics Summit that you would like to hear more about this year, please let us know by filling out the form below by May 1, 2022.

Suggest a Topic or Speaker here

Genetic Ambassador May Call

Our MSRGN Genetic Ambassador group is a place for individuals, families and loved ones impacted by genetic conditions to gather quarterly to connect, share and learn together.

Our next call will be on May 19, 2022 at 11am PT/noon MT/1pm CT/2pm ET. If you would like to join this call or know a family who would like to be included, please contact **Kristi**.

Registration is now OPEN for our May 18th Time 4 Genetics Webinar!

Time 4 Genetics Webinar in May:

Genetic Testing: It's not Rocket Science May 18, 2022 (10am PT, 11am MT, noon CT, 1pm ET)

Guest Speakers:

Daryl A. Scott, MD, PhD
Associate professor at <u>Baylor College</u>
of <u>Medicine</u> & Clinical Geneticist
at <u>Texas Children's Hospital</u>

Haley Streff, MS, CGC
Clinical Instructor at <u>Baylor College of</u>
<u>Medicine</u> & Certified Genetic Counselor
at <u>Texas Children's Hospital</u>



Register Here for May 18 Webinar



https://bit.ly/PMEval22

CONNECTING UNDERSERVED POPULATIONS TO GENETICS

The seven Regional Genetics Networks, NCC, and the Family Center work together to improve access to genetic services for underserved populations. Learn about the impact of our work by checking out the updated interactive dashboard!





Evaluation Dashboard for the Regional Genetics Networks

As a member of MSRGN, did you know that we collect data related to our mission of improving access to genetic services for underserved population? Each RGN, including MSRGN, are required to report data on specific measures so that as a system with the other six RGNs, the National Coordinating Center for the Regional Genetics Networks (NCC), and the National Genetics Education and Family Support Center (Family Center), we can understand the impact of our work.

Each year, the RGN's submit data to the NCC about the number of providers and individuals that are served through our activities (education, training, telehealth support, and assisting connections to genetic services), as well as the clinics we help support to deliver telehealth. This data is then compiled by the NCC to present a national picture of the reach of the system.

On NCC's website (https://nccrcg.org/evaluation-dash/), you can find an interactive dashboard that presents the data and sample activities from June 2017 to May 2021 (through year 4's data).

Have questions about how this data is collected for (RGN)? Reach out to our external evaluator, Liza Creel to learn more.

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
- Cody Price, State Teams Coordinator (transitioning to THI, full time)
- Jamie Stefanski, State Teams Coordinator
- Mekayla Perkins, Projects 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

<u>View as Webpage</u>

Connect with us





