

October 2021

MSRGN Project Directors' Message



# Less Than 2 Weeks Away!!

We are just under 2 weeks away from the MSRGN Genetics Summit, a virtual genetics educational event for our region! We look forward to welcoming 13 speakers on **November 9th and 10th** to share their knowledge, wisdom and resources on a wide variety of topics (agenda here). See some of those topics below as well as a few of ouffeatured speakers and what they will be speaking about below.

Please help us reach our goal of 450 registrants by sharing this email with a colleague, family, list-serve or friend!

Register here for the 2021 MSRGN Genetics SummitVirtual & No Charge!

#### Featured Speakers:

Connecting the...

D - Dr. Francisco Moreno, University of Arizona

Personalized Medicine & Diverse Participation:Perspectives from the All of Us Program in AZ

O - Tara Wenger, MD, PhD, Seattle Children's

Next Generation Genetic Medicine: Practical Pearls for Pediatrics

T - Dr. Kirsten Bennett, NM Quality Improvement Partnership

Providing Community Based Nutrition Services via Telehealth for Young Children

S - Mariah Gillaspie, Lightning and Love Foundation

Living Ultra-Rare: Navigating Diagnosis and Next Steps

# **Featured Speakers**



Dr. Francisco Moreno , Associate Vice President , UAHS, Equity Diversity and Inclusion University of Arizona



Tara Wenger, MD, PhD Associate Medical Director Inpatient Genetics Services Seattle Children's



Dr. Kirsten Bennett NM Quality Improvement Partnership



Mariah Gillaspie Lightning and Love Foundation



Register Now







<u>Time 4 Genetics</u>

<u>Applications OPEN</u>

Join us in

### Wishing Cody Well!

Good news is, he is not going too far!

Cody Price, our MSRGN State
Teams Coordinator, will be
transitioning off the MSRGN project
over the next few months to take
on a new role with Texas Health
Institute. Cody's new title with THI will
be: Health Policy Research Analyst.
While we will miss him greatly at
MSRGN, we are excited where his
new projects will take him and glad
that he will still be part of THI. Over
the next few months we will be
recruiting for a new state teams
coordinator.

The Job Posting is in the works and coming soon. Please stay tuned to the **THI** and **MSRGN** Websites for updates.

Job Posting for Cody's Replacement is Coming Soon!Please Check Here for Updates



#### Meet our MSRGN Colorado Genetic Navigator

Jamie Stefanski email: <u>coloradogenetic@gmail.com</u>

Jamie Stefanski is a Physical Therapist and ABM NeuroMovement Practitioner, a

# Developmental Delays & Genetics CME/CEU Webinar Recording available!

Do you know a pediatrician or family medicine provider in our region who would like to learn more about genetics? Please ask them to apply here to be part of our Time 4 Genetics initiative! Deadline is November 15th.

In September, **Dr. Austin Larson** from Children's Hospital Colorado presented a webinar for our Time 4 Genetics series. The titile of the webinar was:

An Approach to Genetic Diagnosis for Patients with Developmental Delay.

The webinar recording and slides are now available on our website and FREE CME/CEU is available. Please click the link below to access the recording.

Access Developmental Delay & Genetics Webinar Recording & FREE CME/CEU Here

Genetics Book Club!
Join our Time 4 Genetics
Clinics in reading:
The Child Who Never Grew
by Pearl Buck

For the Family Centered
Perspectives month (Topic #2
Developmental Delays) in
November, our Time 4 Genetics
clinics and MSRGN, will be exploring
a mother's perspective (Pulitzer &
Nobel Prize winner, Pearl Buck) on
her child's journey with a genetic
condition (PKU), originally published

mother of two children with the rare genetic disorder TELO2/You-Hoover-Fong Syndrome and has been part of the Mountain States Regional Genetics Network (MSRGN) Colorado State team since 2018. She is also 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 as well as 5 other states previously, so she has experience navigating the medical system, insurance system, special needs, medically complex and genetics worlds as a professional and parent. She looks forward to helping families as a genetics navigator.

> Don't forget! November 15th DEADLINES

<u>Applications</u> for State Team Funding/Projects are DUE!

<u>Applications</u> due for <u>Time 4 Genetics</u> Clinics (Cohort 2)

in 1950.

"It was my child who taught me to understand so clearly that all people are equal in their humanity and that all have the same human rights. None is to be considered less, as a human being, than any other, and each must be given his place and his safety in the world" -Pearl Buck

> Link to Book Here

Check out a new Infographic from Genome.gov

Why was it so difficult to fully complete the human genome sequence?

View Infographic Here

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#### 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

