

December 2021

MSRGN Project Directors' Message



This Holiday Season...
We give to you the
12 Days of Genetic Summit Presentations!

On the first day of the Genetics Summit my true love gave to me... an Ultra-fast metabolizer in a pharmacogenetics tree (Elias)

On the 2nd day of the Genetics Summit my true love gave to me... Two types of Gene Therapy (viral and non-viral) (Lee)

On the 3rd day of the Genetics Summit my true love gave to me... Three multiplied by 800 (=2400) possible

Newborn Screening Conditions (Rohrwasser)

On the 4th day of the Genetics Summit my true love gave to me... Four genetic pearls for pediatric genetic testing (Wenger)

On the 5th day of the Genetics Summit my true love gave to me... Five red flags for autism/genetic/metabolic referral (Kahler/Wees)

On the 6th day of the Genetics Summit my true love gave to me... Six letters to remember (SPIKES) when delivering a difficult diagnosis (Andoni)

On the 7th day of the Genetics Summit my true love gave to me... Seven early intervention specialties (for a transdisciplinary & telehealth approach) (Bennett)

On the 8th day of the Genetics Summit my true love gave to me... <u>Eight Cystic Fibrosis history dots connected (Trivedi)</u>

On the 9th day of the Genetics Summit my true love gave to me... Nine genetic resources for ultra rare diagnoses (Gillespie)

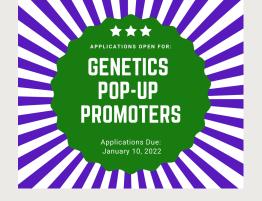
On the 10th day of the Genetics Summit my true love gave to me... Ten life expectancy by zip code and poverty rate graphs (Iton)

On the 11th day of the Genetics Summit my true love gave to me... <u>Eleven states with many of "All of Us" participants (Moreno)</u>

On the 12th day of the Genetics Summit my true love gave to me... <u>Twelve (= 2 sets of 6) Ethical Principles for engaging in genomic research</u> <u>with Indigenous communities (Begay)</u>

Happy Holidays and Happy New Year from all of us at Mountain States Regional Genetics Network

Upcoming January 10, 2022 Deadline for Applications:



Genetics Pop-Up Promoters Application is due 1/10/21

Region- wide Genetic Pop-Ups are coming in Feb/March of 2022! In order to help spread the word, in each of our 8-states, we are recruiting

8 Genetics Pop-Up Promoters.

A \$100 stipend will be paid for those selected to represent their state upon completing (and documenting) 8 promotional activities, to spread the word about the pop-ups. There are 8 open pop-up promoter spots available:

one for each of our eight states-AZ, CO, MT, NV, NM, TX, UT, WY. Does this sound like something you would like to help with? Apply HERE! Application deadline: 1/10/22

Apply to be a Genetics Pop-Up

Promoter



Time 4 Genetics
Applications for
Cohort #2
DUE 1/10/22

We have 8 spaces still 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 <u>apply here</u> to become a Genetics Champion in your state as part of our Time 4 Genetics initiative!

The application deadline has been extended to 1/10/22.

Apply for Time 4 Genetics Cohort #2 Here

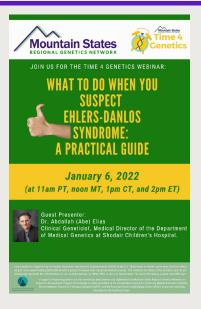


Meet our Montana MSRGN Genetic Navigator

Jennifer Banna

email: Montanagenetic@gmail.com

Jenn Banna's family lives in Montana where she directs Montana's Family to Family Health Information Center. Genetics became a large part of her life when her daughter was diagnosed with Pitt Hopkins Syndrome in 2012. She has been involved with MSRGN as a genetic ambassador, genetic popup presenter and a former Montana team co-load. You can email Jennifer here: montanagenetic@gmail.com



Time 4 Genetics Webinar in January:

What to do when you suspect Ehlers-Danlos Syndrome (EDS): A Practical Guide

January 6, 2022 (11am PT, noon MT, 1pm CT, 2pm ET)

Guest Speker:
Dr. Abdallah (Abe) Elias
Clinical Geneticist, Medical Director of
the Department of Medical Genetics
at Shodair Children's Hospital

Register for Webinar Here

A note about the Genetics Summit~

It has been brought to our attention that the content in one of the presentations at the Genetics Summit was medically detailed and graphic in nature and upsetting to some individuals. As the organizers of this event our intention was not to cause anyone to feel uncomfortable with the content of the talks and we hope the audience will understand that the specifics of how a speaker will present information was outside of the planning committee's control. A notification and content warning has been added to the recording and enduring continuing education page.

Check out the 2021 Genetics Summit Infographic



Please join our colleagues at SERN (Southeast Regional Genetics Network)

Friday, January 28

at **12:00 pm ET**

for the SERN Lunch and Learn Series:

"Pathway to Newborn Screening Facilitated by Collaborations with a Parent Organization

A Case Scenario: GAMT Deficiency"

Their speakers will be 2 of the members of our UTAH state Team:

Heidi Wallis

Executive Director

Association for Creatine Deficiencies

&

Marzia Pasquali, PhD, FACMG

Professor of Pathology
University of Utah
School of Medicine
Section Chief & Medical Director
Biochemical Genetics and Supplemental Newborn Screening

RSVP to attend by registering at the link <u>HERE</u>

If you have any questions, please contact Theresa Pringle at **theresa.pringle@emory.edu**

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