





Message from the Project Directors Kathryn Hassell, MD & Janet Thomas, MD

August 2019

Join Our List.

Join Our List

Dear Friends and Colleagues,

Wow! It is hard to believe that our 2nd annual Genetics Summit is only a MONTH AWAY! We are looking forward to seeing you in Albuquerque. We would love your help in spreading the word, as our team has been working on getting the message out far and wide about our 2019 Genetics Summit. You can help by sharing our posts on social media: Facebook and Twitter or by sharing this link with your colleagues and through list serves. This link will take you directly to our 2019 Genetics Summit web-page where you can find ALL the information including registration, agenda, hotel info, and even information about the artist who painted the Pueblo Zuni DNA artwork you see below.

Register today for the 2019 Genetics Summit!

Listed below are some sessions that will be offered at the 2019 Genetics Summit.



MOUNTAIN STATES REGIONAL GENETICS NETWORK'S

2019 GENETICS SUMMIT

FEATURED SPEAKER

September 23rd - 25th



Albuquerque New Mexico

Improving Timelines of Newborn Screening for Cystic Fibrosis in Utah Fadi Asfour, MD

TO REGISTER: BIT.LY/2019GENETICSSUMMIT

Improving Timelines of Newborn Screening for Cystic Fibrosis in Utah-Speaker Fadi Asfour, MD. This presentation will highlight Utah's experience in improving TAT for newborn screening for CF through collaboration between the clinic and the NBS Program.



Reflections on Anticipation-Speaker Celia Kaye, MD, PhD. This presentation will highlight the major advances in molecular biology over the past century have led to the development of clinical genetics as a medical discipline. Initial concepts about inheritance and biology evolved, resulting in enhanced appreciation of disease mechanisms and possible treatments. Early methods of diagnosis and treatment gave way to more sophisticated approaches, resulting in changes in the roles of clinicians. Federal agencies adopted genetics as an important field for research, surveillance and population-based preventive strategies. This presentation will describe the broad scope of these changes and their impact on practitioners, patients and families.

When: September 23rd-25th, 2019

Where: Marriott Albuquerque Registration: Online here

Agenda: here

State Team Spotlight: New Mexico

The New Mexico State Team will be piloting a telehealth clinic for metabolic disorders in the Farmington Public Health Clinic. The team is also partnering with the Prader-Willi Syndrome Association in New Mexico to develop educational sessions for families and providers.

Colorado's Newborn Screening Virtual Education Series

The Colorado State Team's next virtual education session is scheduled for Sept 10th from 12 pm to 1 pm MT on "Hemoglobinopathies and Endocrine Disorders." This activity, designed for the primary care providers and interdisciplinary healthcare teams, will include a review of current newborn screening disorders screened by the Colorado Newborn Screening Program for Colorado and Wyoming.

For more information on how to register for this event click here.

Consumer Orientation Call

If you are a consumer and are planning on attending the 2019 Genetics Summit, we would like to invite you to join us for a consumer orientation call. Please choose one session that works best for your schedule (Sept 3rd 12 pm-1pm CT or Sept 9th 12 pm-1pm CT). We will also be recording the call for those who schedule precludes them from joining either session. We look forward to seeing you in Albuquerque. Please contact Kristi Wees if you have any questions.

Topic: Consumer orientation call #1

Time: Sep 3, 2019 12:00 PM Central Time (US and Canada)

Join Zoom Meeting

https://zoom.us/j/249168592

Topic: Consumer orientation call #2

Time: Sep 9, 2019 12:00 PM Central Time (US and Canada)

Join Zoom Meeting

https://zoom.us/j/556705318

Facebook Live

If you missed our last Facebook Live on "Your Genetic Questions Answered About Developemental Delays & Genetics" with Dr. Abe Elias and Jaclyn Haven, CGC, MS from Shodair Children's Hospital in Montana, please click here.

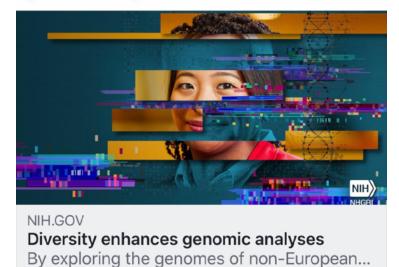
Facebook Post of the Month

To read more about "Diversity enhances genomic analyses," click here.



Diversity enhances #genomic analyses

"These findings underscore the importance of including people from different racial and ethnic groups in research studies." https://www.nih.gov/news-events/nih-research-matters/diversity-enhances-genomic-analyses



To read how "A family's medical mystery sheds light on the surprising ways disease-causing genes can be inherited," click here.



#medical mystery solved for one family-#genetics

"Heritable diseases — say Huntington's, sickle cell anemia, or cystic fibrosis — are typically thought of as the result of a certain mutation in one #gene. But sometimes, variants of a few genes collectively cause what are called "#oligogenic" diseases."

https://www.statnews.com/2019/07/08/ genetics-family-heart-disease/



STATNEWS.COM Medical mystery sheds light on the surprising ways genes can be inherited

Thanks for Sharing!

We have wonderful members of our Genetics network who frequently share links, articles, publications, etc. with us that they think others might find interesting. We will be highlighting some of those resources here in upcoming newsletter take a peek at this resource: Center for Disease Control and Prevention's Good Health and Wellness in <u>Indian Country (GHWIC)</u>, shared by <u>Daphne Fulton</u> a member of the Texas State Team.

GHWIC Table of Contents

- Good Health and Wellness in Indian Country: A New Partnership and Approach Bauer UE, Espey DK
- A Holistic Approach to Chronic Disease Prevention: Good Health and Wellness in **Indian Country** Andrade NS, Espey DK, Hall ME, Bauer UE
- Creating a Public Health Community of Practice to Support American Indian and Alaska Native Communities in Addressing Chronic Disease Williams SL, Kaigler A, Armistad A, Espey DK, Struminger BB
- Obesity and Diabetes in the Winnebago Tribe of Nebraska: From Community Engagement to Action, 2014-2019 Alonso L, Decora L, Bauer UE

- Improving the Health of Alaska Native People Through Use of a Policy Change <u>Model and Capacity Building</u>
 Redwood D, Mitchell-Box K, Peterson E, Provost E
- <u>Good Health and Wellness: Measuring Impact Through an Indigenous Lens</u> Lawrence T, James R

<u>Tribal Practices for Wellness in Indian Country</u>
Andrade NS, Jones M, Frazier SM, Percy C, Flores M Jr, Bauer UE

FOLLOW MSRGN ON TWITTER

MSRGN is now on Twitter. Please follow us <u>@GeneticMtnState</u>

July Jana Jras Jras

Email Communications from MSRGN

MSRGN is in the process of updating our contact list. If you would like to update your email preference or do not wish to receive communications from MSRGN, please email Annette Lara.

Warm regards,

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www.MountainStatesGenetics.org

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