



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

September 2018

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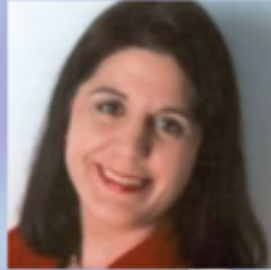
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Dear Friends and Colleagues,

Fall is arriving this month in our beautiful mountain states, as the temperatures start to cool down and the leaves start to turn colors. We are weeks away from our 2018 Genetic Summit and are finishing last minute details to ensure this is a memorable meeting for all.

**Register today for the 2018 Genetics Summit
Limited Spaces Available**

Featured Speakers



Tales from the Trenches: Consumer Advocacy on the Journey

- Allysia Seymour, Member, MSRGN New Mexico State Team, Pueblo of Laguna
- Susan Owens, Lead, Autism Oxalate Project, Autism Research Institute
- Heidi Wallis, Vice President, Association for Creatine Deficiencies
- Joel Lopez, Engagement and Outreach Manager, Genetic Alliance, The National Genetics Education and Family Support Center
- Kristi Wees, MsChem MSRGN, Moderator

2018 GENETICS SUMMIT

ACCESSING GENETICS CARE IN OUR REGION

OCTOBER 2-3, 2018

FOR MORE INFO: WWW.MOUNTAINSTATESGENETICS.ORG/EVENTS/GENETICS-SUMMIT/

When: Oct 2-3, 2018

Where: [Courtyard San Antonio Riverwalk](#)

Registration fees: \$75 for CE's (CME, CNE, SW, or Genetic Counselors)
\$50 non CE's

Registration: Online [here](#)

Agenda: [here](#)

Listed below are is a session that will be offered at the **Summit:**

Tales from the Trenches: Consumer Advocacy on the Journey- Speaker: Allysia Seymour, Susan Owens, Heidi Wallis, Joel Lopez, and Kristi Wees.

This presentation will highlight the real-life experiences and stories behind the genetic testing and diagnostic journeys as shared by those families impacted by genetic conditions of their children or family members. The panel discussion will highlight families with very diverse experiences in the medical and genetics world. In addition to the panel, Joel Lopez from the National Genetics Education & Family Support Center will share insights, resources, and guidance on improving family engagement of those impacted by genetic conditions.

IHS Clinical Rounds: Nutritional Management of Genetic Disorder

Melissa Sailer, MS, RD, CNSC will be presenting on Nutritional Management of Genetic Disorders that will identify macronutrients involved in inborn errors of metabolism and goals of nutrition therapy, along with all nutritional considerations. Basic dietary treatment and intervention will be described for disorders of amino acid, organic acid, urea cycle, carbohydrate (galactose and glycogen) and fat (long-chain and very-long chain fatty acid) metabolism. This presentation will also provide an in-depth description of a galactose restricted diet along with an amino acid restricted diet and the importance of medical food, low protein food, whole protein foods and nutritional supplements

The webinar is scheduled for September 27th from 2pm-3pm CST. Information on how to register for this webinar can be found on the MSRGN website on this [link](#).

State Team Spotlight: Montana

Montana State Team has developed a provider survey in order to assess how well the Shodair Children's Hospital Department of Medical Genetics is meeting the needs of stakeholders and colleagues. The information gained from survey participants will allow the team to identify their accomplishments and areas for improvement. The data will be used to pursue supplemental funding sources to support the growth and development of the genetics program. As an incentive, the team is offering \$20 gas cards to the first 60 participants. If you know a pediatric provider, specialist, pediatrician or family physician in Montana who would like to take the survey, please contact [Annette Lara](#) so she can connect you with the team to access the survey. (Survey is restricted to providers in Montana)

Texas Pediatric Conference

The Texas State Team was an exhibitor at the [Texas Pediatric Conference](#) in San Antonio, TX on Sept 6th and 7th. The team answered questions about genetics and collected surveys from pediatricians at the conference.



Elizabeth Roeder, MD, geneticist at the Children's Hospital of San Antonio, and Debra Freedenberg, MD, Ph.D, Medical Director Newborn Screening and Genetics Unit, Texas Department of State Health Services



Scott McLean, MD, geneticist and Rebecca Littlejohn, Genetic counselor from the Children's Hospital of San Antonio.



Scott McLean, MD, geneticist at the Children's Hospital of San Antonio

Facebook Post of the Month

**State Specific Fact Sheets on
Medicaid and CHIP from
American Academy of
Pediatrics
(See comments)**

<https://www.aap.org/en-us/advocacy-and-policy/federal-advocacy/Pages/Childrens-Health-Care-Coverage-Fact-Sheets.aspx>

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MSRGN is now on Twitter. Please follow us [@GeneticMtnState](https://twitter.com/GeneticMtnState)

Warm regards,



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Website:**

www.MountainStatesGenetics.org

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