

Virtual Conference Series

MSRGN Genetics Summit: Connecting the Dots

November 9 th 5 hour block (proposed 9 total CEU hours)	
Time (CT)	Session Details: Disease & Diagnosis
10:30 am- 10:40 am	<p>Welcome & Opening Remarks: Setting the Stage</p> <ul style="list-style-type: none"> • Welcome • Attendee Website overview (chat, q&A, CEU, etc) • MSRGN & Summit overview
10:40 am- 11:20 am	<p>Gene Therapy: History, Current State, and Looking to the Future</p> <p>We will review the key milestones in the development of gene therapy, the major approaches, advantages and disadvantages of each, and the future applications and ethical considerations for rapid expansion of gene therapy applications.</p> <p>Presenter: Brendan Lee, MD, PhD Professor and Chairman Baylor College of Medicine/Dept. of Molecular and Human Genetics</p> <ul style="list-style-type: none"> • 30 min presentation • 10 min Q&A
11:20 am- 12:00 pm	<p>Personalized Medicine and Diverse Participation: Perspectives from the All of Us Program in Arizona</p> <p>We will discuss the diversity representation limitation and its impact. Will describe the All of Us Research Program, its values and priority strategies. Will discuss the approaches utilized by the University of Arizona/Banner Health Engagement strategies, sharing challenges and successes.</p> <p>Dr. Francisco Moreno Associate Vice President UAHS, Equity Diversity and Inclusion University of Arizona</p> <ul style="list-style-type: none"> • 30 min presentation • 10 min Q&A
12:00 pm- 12:10 pm	Break
12:10 pm- 12:50 pm	<p>The Future of Newborn Screening</p> <p>In this session we will discuss change requirement for current Newborn screening programs or systems. Based on rapidly increasing disorders that would benefit from presymptomatic identification, we will explore needs for changing testing infrastructure and explore alternative modes of testing delivery.</p> <p>Presenter: Dr. Andy Rohrwasser Director Utah Public Health Laboratory</p>

	<ul style="list-style-type: none"> • 30 min presentation • 10 min Q&A
12:50 pm-1:10 pm	LUNCH
Time (CT)	Session Details: Outreach
1:10 pm-1:50 pm	<p>Next Generation Genetic Medicine: Practical Pearls for Pediatrics</p> <p>In the past 5 years there have been significant advances in diagnostic testing, including new methodologies (e.g. preimplantation genetic testing, cell-free DNA, exome and genome sequencing) as well as more options for rapid testing. We will discuss new diagnostic testing and what providers should know about strengths and limitations of the new testing.</p> <p>Precision therapeutics for genetic testing have evolved significantly over the past several years, allowing treatment for genetic disorders that were previously not treatable or were difficult to treat. We will discuss recent advances and what providers can do to find out if there are new options for their patients with genetic disorders.</p> <p>Presenter: Tara Wenger, MD, PhD Craniofacial Pediatrician and Geneticist Seattle Children's</p> <ul style="list-style-type: none"> • 30 min presentation • 10 min Q&A
1:50 pm-2:30 pm	<p>Beyond the M-CHAT: Autism as a Systemic Condition</p> <p>In this talk, Dr. Stephen Kahler (geneticist) and Kristi Wees (family leader, patient advocate and parent) will explore the medical co-morbidities that can occur with Autism Spectrum Disorders (ASD) and the role for the clinical and biochemical geneticist as guidance for primary care providers and families.</p> <p>The different presentations of ASD (e.g., gradual awareness or sudden regression) will be explored, as well as typical and atypical features in the family history and exam which may be a red-flag for genetic or metabolic referrals. In addition, the role of different specialists (including geneticists) and laboratory testing in the evaluation of ASD will be explored through the medical lense as well as the collective stories and anecdotes of family experiences.</p> <p>Presenters: Stephen Kahler, M.D. Professor Department of Pediatrics, University of Kentucky</p> <p>Kristi Wees, MSChem Projects Manager, Mountain States Regional Genetics Network Family Leader & Empowered Parent</p> <ul style="list-style-type: none"> • 30 min presentation • 10 min Q&A
2:30 pm-2:40 pm	Break

2:40 pm- 3:20 pm	<p>Delivering a Difficult Diagnosis with Hope</p> <p>Too often we hear stories of people having negative experiences of receiving difficult information from their healthcare providers. Patients may leave these encounters feeling confused and seeking answers. Delivering difficult news effectively is a complex, important communication skill. The way news is delivered can impact an individual's or family's reaction to and understanding of the information. Thankfully, there is literature about preferences for how to receive news, models for providing news and information about training methods for this skill. Hopefully together we can work towards improving the delivery of difficult news so that patients can have more positive, supportive experiences.</p> <p>Presenter: Laila Andoni, MS, CGC Genetic Counselor Intermountain Healthcare</p> <ul style="list-style-type: none"> • 30 min presentation • 10 min Q&A
3:20 pm- 3:30 pm	<p>Closing</p> <ul style="list-style-type: none"> • Survey, CEU • Next steps/session

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November 10th: 5 hour block (proposed 9 total CEU hours)	
Time (CT)	Session Details: Total Value
10:30 am- 10:40 am	<p>Welcome & Opening Remarks: Setting the Stage</p> <ul style="list-style-type: none"> • Welcome back • Attendee Website reminders (chat, q&A, CEU, etc) • Day 2 announcements
10:40 am- 11:20 am	<p>Breath from Salt: A History of Cystic Fibrosis from Characterization to (Almost) Cure</p> <p>This presentation will begin with a reading from <i>Breath from Salt</i>. I'll describe the main characters in the book: the parents who created the CF Foundation, the scientists who led the pathbreaking research, the chemists who designed the personalized medicines that now treat 90 percent of patients with this disease, and the fundraisers and philanthropists who funded all the early R&D.</p> <p>Presenter: Ms. Bijal Trivedi Author</p>

	<p>Senior Science Editor, National Geographic</p> <ul style="list-style-type: none"> • 30 min presentation • 10 min Q&A
11:20 am-12:00 pm	<p>Adding Value to Pharmacogenetics An integrated delivery model of pharmacogenetic-guided medication management for the rural health care setting.</p> <p>Presenter: Dr. Abdallah F. Elias Medical Director, Department of Medical Genetics Shodair Children’s Hospital</p> <ul style="list-style-type: none"> • 30 min presentation • 10 min Q&A
12:00 pm-12:10 pm	Break
12:10 pm-12:50 pm	<p>Providing Community Based Nutrition Services via Telehealth for Young Children Families of young children require additional support even without the added stress of raising a child living with a genetic condition. These children may have co-occurring developmental delays and concerns. The transdisciplinary approach to family support in Early Intervention maximizes opportunities to support optimal development.</p> <p>Presenter: Dr. Kirsten Bennett Bennett Nutrition and Consulting and NM Quality Improvement Partnership</p> <ul style="list-style-type: none"> • 30 min presentation • 10 min Q&A
12:50 pm-1:10 pm	LUNCH
Time (CT)	Session Details: Social Perspectives
1:10 pm-1:50 pm	<p>When It Comes to Your Health, Does Your Zip Code Matter More Than Your Genetic Code? In 2013 when Forbes magazine listed the top ten healthcare quotes for 2013, the number one quote was attributed to me: “When it comes to health, your zip code matters more than your genetic code.” This brief presentation will address some of the data and evidence behind that quote by exploring the strength of the relationship between life expectancy and neighborhood. Using hundreds of thousands of death certificates, GIS mapping and other simple data analyses, a profile of life expectancy by neighborhood in seven different cities and regions will be presented. The implications for US health spending and population health management will be discussed and a model for understanding the social determinants of health will be presented.</p> <p>Presenter: Dr. Tony B. Iton Senior Vice President The California Endowment</p>

	<ul style="list-style-type: none"> • 30 min presentation • 10 min Q&A
1:50 pm- 2:30 pm	<p>Ethical Genomic Research with Indigenous Communities</p> <p>Presentation on the challenges and barriers to genomic research with Indigenous people and how a set of ethical principles can be employed to ethically engage with the community. This framework is a start to correcting the harms and maximizing the benefits for Indigenous communities.</p> <p>Presenter: Rene Begay, MS Research Assistant University of Colorado Anschutz Medical Campus School of Public Health</p> <ul style="list-style-type: none"> • 30 min presentation • 10 min Q&A
2:30 pm- 2:40 pm	Break
2:40 pm- 3:20 pm	<p>Living Ultra-Rare: Navigating Diagnosis and Next Steps</p> <p>What happens when genetic testing doesn't provide a diagnosis? Or what if it does, but medical science knows very little about your particular gene? As a mother of the only two known people in the world living with their particular genetic disease, I am sharing my experience living ultra-rare and the resources that I have used on my journey from undiagnosed to founder of the Lightning and Love Foundation for THAP12 research.</p> <p>Presenter: Mariah Gillaspie Lightning and Love Foundation</p> <ul style="list-style-type: none"> • 30 min presentation • 10 min Q&A
3:20 pm- 3:30 pm	Closing <ul style="list-style-type: none"> • Survey, CEU • Next steps/session