

OCTOBER 2021

GENETIC AMBASSADORS

Mountain States Regional Genetics Network

October 28, 2021



MSRGN'S FUNDING

This program is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$600,000.00 with 0 percent financed with non-governmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more information, please visit [HRSA.gov](https://www.hrsa.gov).



WHO IS MSRGN?



AGENDA

- **INTRODUCTIONS**
- **GENETIC SUMMIT**
- **GENETIC EXPLAINER
VIDEOS**
- **BRAINSTORMING ON
FUTURE PROJECTS**
- **TIME 4 GENETICS**



INTRODUCTIONS



INTRODUCTION

QUESTION

Question:
What is your favorite
Genetics resource that
helped your family or that
you have shared with
others?



INTRODUCTIONS





KRISTI WEES, MS

Projects Manager

MSRGN













RED FLAGS 4 GENETICS HANDOUT

<https://www.mountainstatesgenetics.org/redflagnews/>



RED FLAGS 4 GENETICS


Do you have concerns about your child?
Below are **red flags** or warning signs and symptoms that were self-reported by families whose child went on to receive a genetic diagnosis. 89% of reported **red flags** were noted before 4 years of age.

 <h3>Developmental Delay</h3>	 <ul style="list-style-type: none">Physical/motor delay (not rolling over, crawling or walking)Speech (not babbling or responding to name)Adaptive (coordination of hands and fingers)	<ul style="list-style-type: none">Cognitive (unable to or not interested in play)Social/emotional (difficulty interacting with others, not smiling)Loss of any milestone (regression)
 <h3>Physical Features</h3>	<ul style="list-style-type: none">Extra fingers or toesLarge/small head size (macrocephaly/microcephaly)Short/tall height (stature)	<ul style="list-style-type: none">Cleft palateFacial feature differences (small chin, wide forehead)Frequent joint dislocations (hip dysplasia)Spinal deformities (scoliosis) 
 <h3>Feeding Issues</h3>	 <ul style="list-style-type: none">Difficulty swallowingStruggles with breastfeedingPoor latchingFeeding tube dependent	<ul style="list-style-type: none">Never feeling fullPoor appetiteVomitingGagging on food
 <h3>Behavior</h3>	<ul style="list-style-type: none">Autism Spectrum Disorder (ASD)Repetitive movementsConstantly upset or cryingLack of eye contact	<ul style="list-style-type: none">Difficulty in school or social settingsADHD/impulsive or hyperactive behaviorEasily distractedHigh pitched cry/tone of voice 
 <h3>Failure To Thrive</h3>	 <ul style="list-style-type: none">Slow growthSlow weight gainNot thriving	<ul style="list-style-type: none">Fatigues quickly when activeWeight or rate of weight gain being much lower than that of other children.
 <h3>Strength & Tone</h3>	<ul style="list-style-type: none">Floppy or low muscle tone (hypotonia)Stiff or high muscle tone (hypertonia)Baby not attempting to roll over or hold head up when on tummy	<ul style="list-style-type: none">Muscle weaknessBody is floppyInability to lift or control head (head lag) 

Other Red Flags


- Seizures
- Sleep concerns
- Fatigue
- Lethargy
- Hearing/vision concerns
- Immune issues

- Headaches/migraines
- Neurological concerns
- Pulmonary/cardiac concerns
- GI issues (reflux/bowel concerns)
- Bruising



If your child is exhibiting any **'red flags'** on this page please talk to your child's pediatrician or primary care physician. For more resources and help having that conversation, go to:

www.mountainstatesgenetics.org/redflag

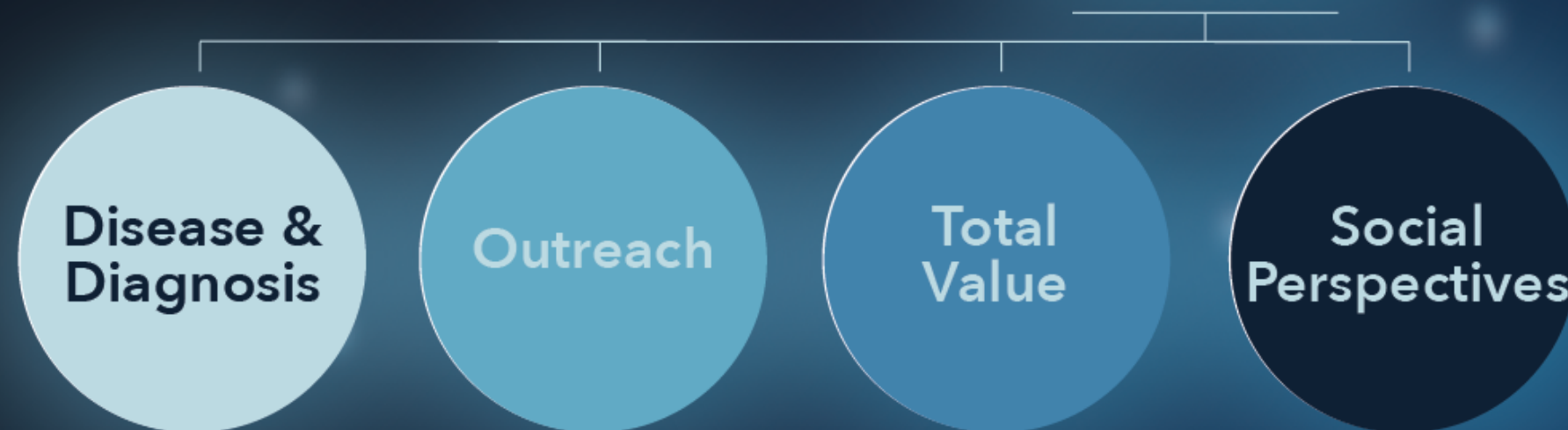


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GENETICS SUMMIT: CONNECTING THE DOTS

MSRGN GENETICS SUMMIT 2021 CONNECTING THE DOTS

Connecting the **DOTS**



GENETICS SUMMIT OVERVIEW

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Gene Therapy:
History, Current State, and
Looking to the Future



Disease and Diagnosis

Brendan Lee, MD, PhD

Professor and Chairman
Baylor College of Medicine/Dept of
Molecular and Human Genetics

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Disease and Diagnosis

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The Future of
Newborn Screening



Disease and Diagnosis

Dr. Andy Rohrwasser

Director
Utah Public Health Laboratory

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



Disease and Diagnosis

Dr. Francisco Moreno

Associate Vice President UAHS,
Equity Diversity and Inclusion
University of Arizona

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Outreach


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Next Generation Genetic
Medicine:
Practical Pearls for Pediatrics




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




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Beyond the M-CHAT:
Autism as a Systemic Condition



Stephen Kahler, M.D.
Professor
Department of Pediatrics,
University of Kentucky



Kristi Wees, MSChem
Projects Manager,
Family Leader
and Empowered Parent
Mountain States Regional Genetics Network



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Delivering a Difficult
Diagnosis with Hope



Laila Andoni, MS, CGC
Genetic Counselor
Intermountain Healthcare



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Opening & Breath from Salt:

A History of Cystic Fibrosis

from Characterization to

(Almost) Cure



Ms. Bijal Trivedi

Author & Senior Science Editor

National Geographic

Mountain States

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Total Value

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Adding Value to

Pharmacogenetics



Dr. Abdallah F. Elias

Medical Director,

Department of Medical Genetics

Shodair Children's Hospital

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Providing Community

Based Nutrition Services via

Telehealth for Young Children



Dr. Kirsten Bennett

Bennett Nutrition and

Consulting and NM

Quality Improvement Partnership

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GENETICS SUMMIT OVERVIEW

Social Perspective

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When It Comes to
Your Health, Does Your
Zip Code Matter More
Than Your Genetic Code?



Social Perspectives

Dr. Tony B. Iton

Senior Vice President
The California Endowment

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Ethical Genomic Research
with Indigenous Communities



Social Perspectives

Rene Begay, MS

Research Assistant
CU Anschutz Medical Campus
School of Public Health

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Living Ultra-Rare:
Navigating Diagnosis
and Next Steps



Social Perspectives

Mariah Gillaspie

Lightning and Love Foundation

Mountain States

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GENETIC EXPLAINER VIDEOS

<https://www.youtube.com/watch?v=i6wlh8GLx7U>



DISCUSSION...

YEAR 5 FOR GENETIC AMBASSADORS

PROJECT IDEAS

SPEAKER IDEAS

TRAINING IDEAS

Caregiver burnout- Beginning Burnout Day of diagnosis... taking in so much info what did I wrong what can I do reassuring (beyond yoga/ candles. etc.) we are here to help/comfort guilt
EDHI talk about thoughts mental brain processing, fatigue, part 2
Getting Genetics paid for - navigating insurance
EPSDT info
How can F2FHIC help?
Genetic Testing Info-what each type of test is and what is it testing for?
Empower families- question to ask, expectations: after visit summary
Sheet for your first genetics appt- what to bring, what to expect, how to prepare for the appointment

Add a subheading

Empower families: questions written down, binder, next steps, notebook
--

3 REMINDERS...

IN LESS THAN 2
WEEKS!

CAN WE REACH 500?

2021
GENETICS SUMMIT

NOVEMBER 9-10TH

MORE INFO HERE
REGISTRATION
OPENING AUG.

GENETIC
NAVIGATORS

MEET THEM HERE

TIME 4 GENETICS
COHORT #2
APPLICATION OPEN

LINK CAN BE
SHARED WITH
INTERESTED
CLINICS

TIME 4 GENETICS

Do you have a pediatrician or family doc that would like some more genetics education?

Application deadline: November 15th

<https://www.mountainstatesgenetics.org/t4info/>

Video:

<https://www.youtube.com/watch?v=baLf2435Hz4>



THANK YOU!

Thank you for your time today!

If we can be of further assistance,
please reach out to:

Kristi Wees
Projects Manager

email:
kwees@mountainstatesgenetics.org
cell:
281-831-3481

Thank
you!