

August 2021

MSRGN Project Directors' Message



As the summer of 2021 wraps up, we are excited to announce that registration is OPEN for our Genetics Summit 2021: Connecting the Dots. Please check out the Agenda: here and Register: here.

We have 12 amazing speakers who will be connecting the D O T S over 2 days, virtually through 4 themed sessions with 3 talks in each session:

D is for *Disease & Diagnosis* where we will explore topics specific to genetic diagnoses through gene therapy, personalized medicine and newborn screening.

O is for *Outreach* where the speakers will focus on topics that are relevant for the primary care providers in our region who are working with families impacted

by genetic conditions. Topics will include genetic testing, autism and delivering news or diagnoses to families with hope.

T is for *Total Value* which will cover topics that influence financial, quality, delivery and history of genetic care. Speakers will talk about the cystic fibrosis history, pharmacogenetics, telehealth & nutrition.

S is for *Social Perspectives*. This group of speakers will address social and psychosocial perspectives around genetics conditions through talks on the topics of zip code influenced social determinants of health, indigenous communities and navigating an ultra rare genetic diagnosis.

Also see below to learn about some of our featured speakers and what they will be speaking about.

Register here for the 2021 MSRGN Genetics
Summit





Celebrate Newborn Screening Awareness Month

Share what newborn screening means to you!

Daby's

All are invited to our:

# Time 4 Genetics Webinar:

September 30, 2021

(at 11am PT, noon MT, 1pm CT, and 2pm ET)

# Topic: <a href="Developmental">Developmental</a> <a href="Delays & Genetics">Delays & Genetics</a>

Speaker: Austin Larson, MD Colorado Children's Hospital

The primary audience for this

# September is Newborn Screening Awareness Month

Check out these resources and upcoming events (click on words in **bold** for more info):

#2021 NBS Toolkit from Expecting Health

2021 NBSTRN Summit September 1-3

webinar will be pediatric and primary care providers, however all who are interested in learning more about this topic are welcome to register and attend.

Register Here for Webinar



Meet our MSRGN Arizona Genetic Navigator Noan Dublinski

email: arizonagenetic@gmail.com

Noan Dublinski has been working in Arizona with children who are deaf/hard of hearing for over 25 years as a teacher, audiologist, and currently as an early intervention provider. Noan has her Master's degree in Audiology and her Bachelor's Degree in Deaf Education. Noan's youngest daughter was diagnosed in infancy with cystic fibrosis, a progressive genetic disease. Noan's work and life experience have fueled her desire to support families in accessing genetic information and in advocating for those children receiving genetic diagnoses. Please send her an email welcoming her to MSRGN and contact her for more information on her role in Arizona.

NBS Bootcamp starts Sept 13 from Every Life Foundation & Baby's First Test

APHL NBS Symposium October 5-14

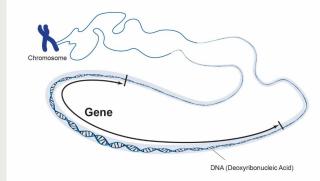
Online Newborn Screening
Training Module for Families:
Navigating Newborn Screening
from Expecting Health
available anytime

# Did You Know?

The word gene may not mean the same thing to all people.

&

The number of genes in the human body may not be as exact of a number as you may think!



Turns out defining the word and concept of a "gene", which is such a cornerstone to the world of genetics, is not as easy as you would think! Since it is challenging to find a common uniting definition, it is also challenging to count the number of genes in an organism (like us!). We came across the 2 articles below that give a glimpse into the world of molecular biology and the complexities of life! We would love to know your definition of a gene as MSRGN is working on explainer videos to help families understand these concepts that even the "gene-hunters" grapple with daily! Send us an email!

Article 1 and Article 2 Photo source: NHGRI

# Featured Speakers



Brendan Lee, MD, PhD Baylor College of Medicine



Stephen Kahler, MD University of Kentucky Pediatrics



Bijal Trivedi National Geographic



Dr. Tony B. Iton The California Endowment



### Featured Speakers: Connecting the...

D - Brendan Lee, MD, PhD, Professor and Chairman, Baylor College of Medicine/Dept of Molecular and Human Genetics Gene Therapy: History, Current State, and Looking to the Future

O - **Stephen Kahler, MD**, Professor, Department of Pediatrics, University of Kentucky

Beyond the M-CHAT: Autism as a Systemic Condition

T - **Bijal Trived**i, Author & Senior Science Editor, National Geographic

Breath from Salt: A History of Cystic Fibrosis from Characterization to (Almost) Cure

S - Dr. Tony B. Iton, Senior Vice President, The California Endowment When It Comes to Your Health, Does Your Zip Code Matter More Than Your Genetic Code?

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