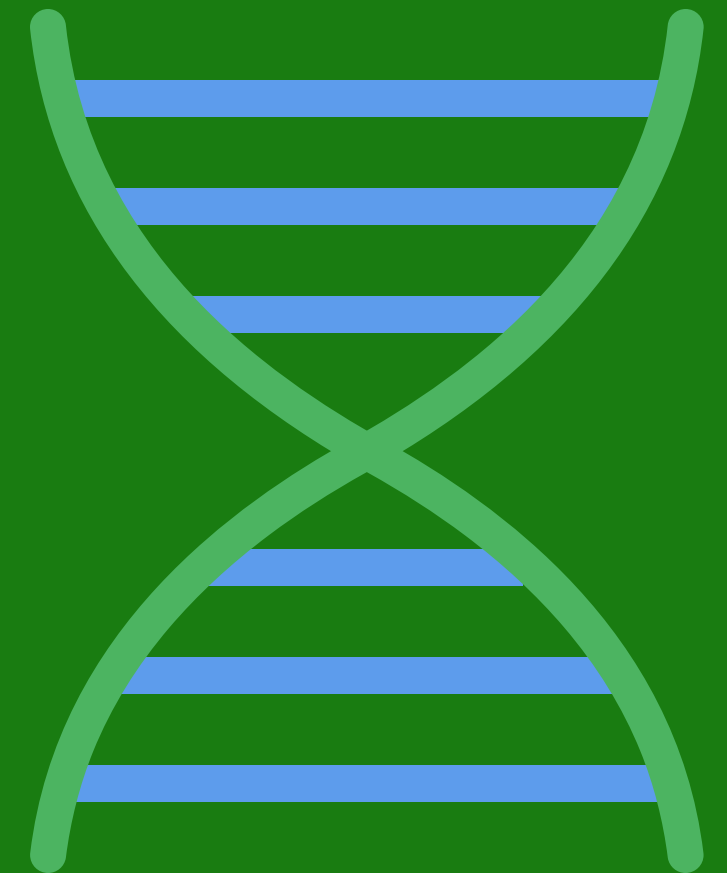
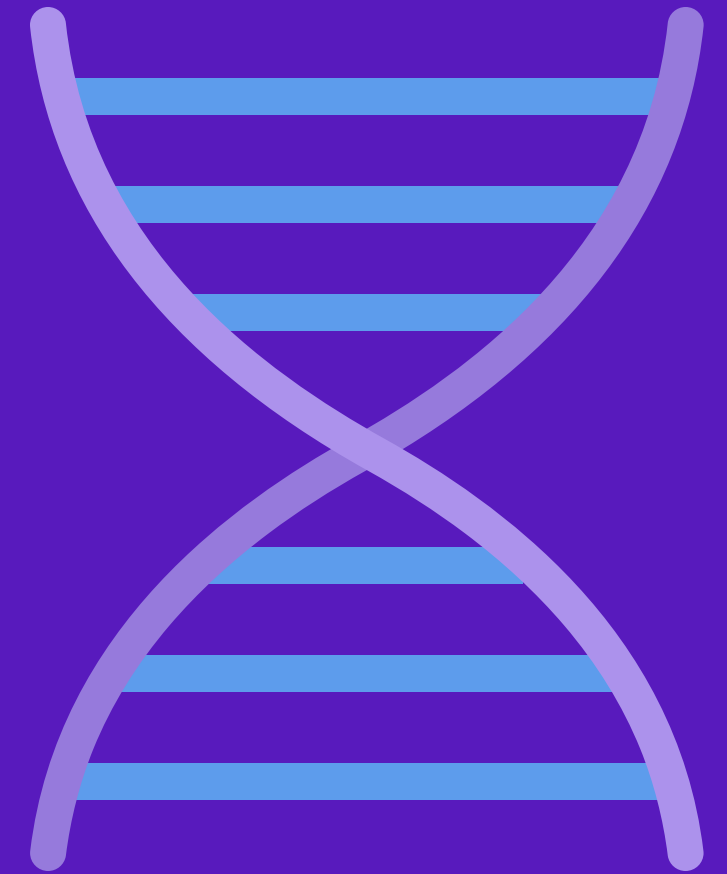


GENETIC AMBASSADORS

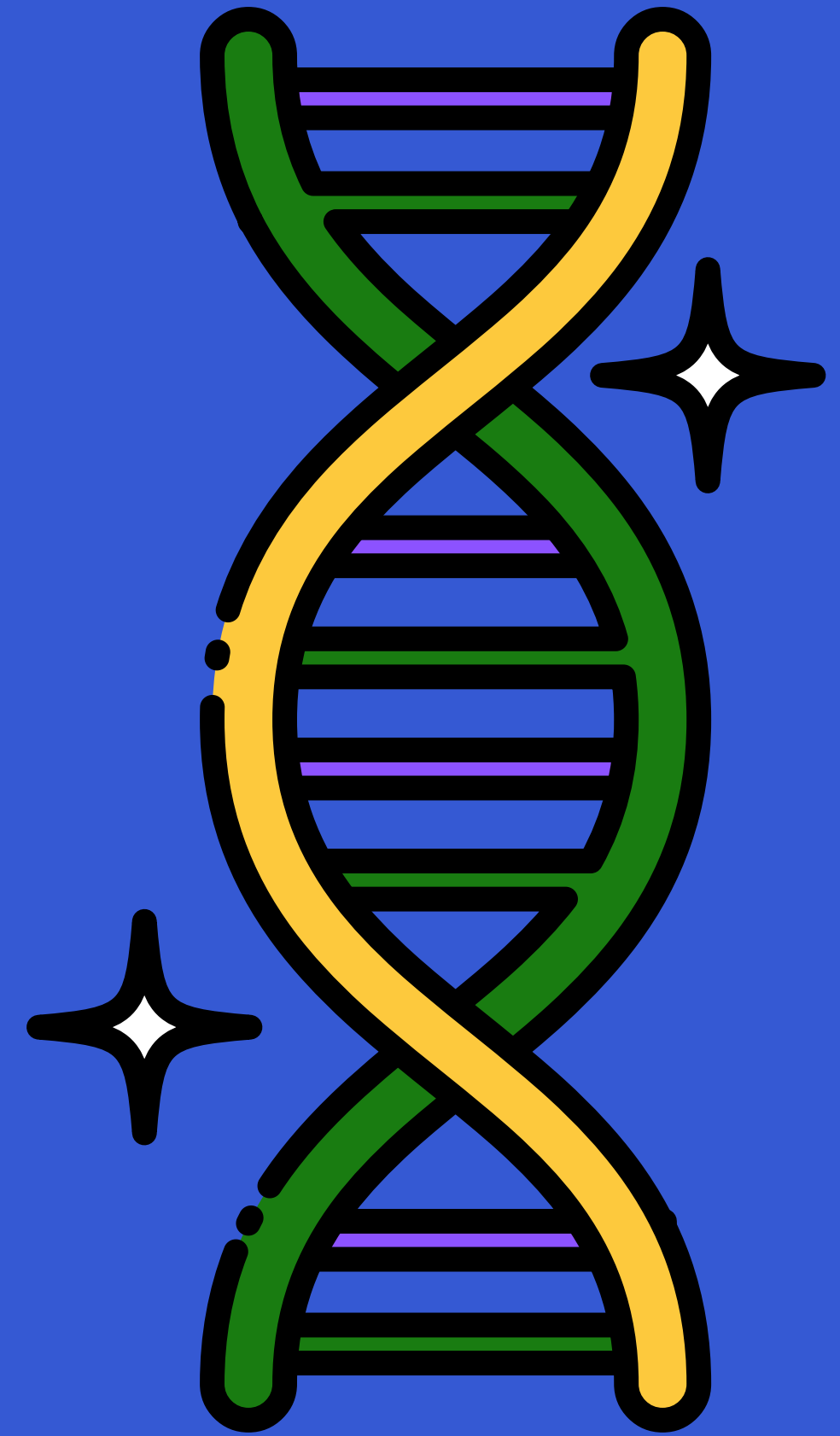
Mountain States Regional Genetics Network

July 27, 2021



AGENDA

- **INTRODUCTIONS**
- **GUEST SPEAKER**
- **RED FLAGS 4**
- **GENETICS HANDOUT**
- **GENETIC EXPLAINER**
- **VIDEOS**
- **DISCUSSION ON**
- **FUTURE PROJECTS**



INTRODUCTIONS



INTRODUCTION

QUESTION

Question: What was the most difficult genetic word or concept to comprehend or understand for yourself or loved one?



INTRODUCTIONS



KRISTI WEES, MS

Projects Manager

MSRGN

INTRODUCTIONS: GUEST SPEAKER



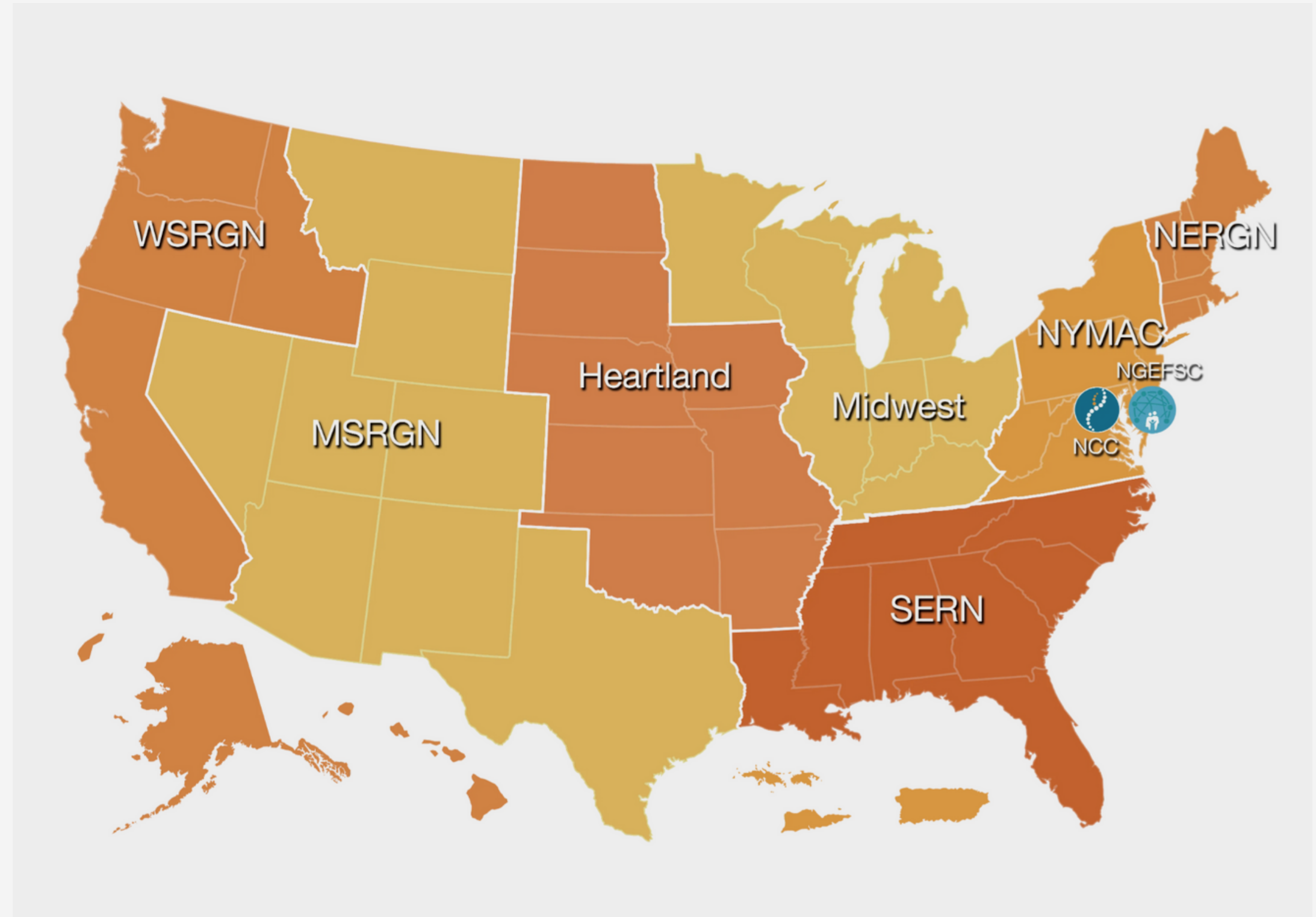
DR. NARA SOBREIRA, MD, PHD

Assistant Professor of Genetic Medicine
Johns Hopkins University School of Medicine
Gene Matcher

WHO IS MSRGN?



PART OF A NATIONAL NETWORK



MSRGN'S MISSION:

The seven Regional Genetics Networks (RGNs), the National Genetics Education and Family Support Center (Family Center), and the National Coordinating Center for the Regional Genetics Networks (NCC)
mission is to improve access to quality genetic services for medically underserved populations.




MSRGN'S FUNDING

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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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GENETIC EXPLAINER VIDEOS

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



DISCUSSION...

YEAR 5 FOR GENETIC AMBASSADORS

PROJECT IDEAS

SPEAKER IDEAS

TRAINING IDEAS

3 REMINDERS...

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

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!