

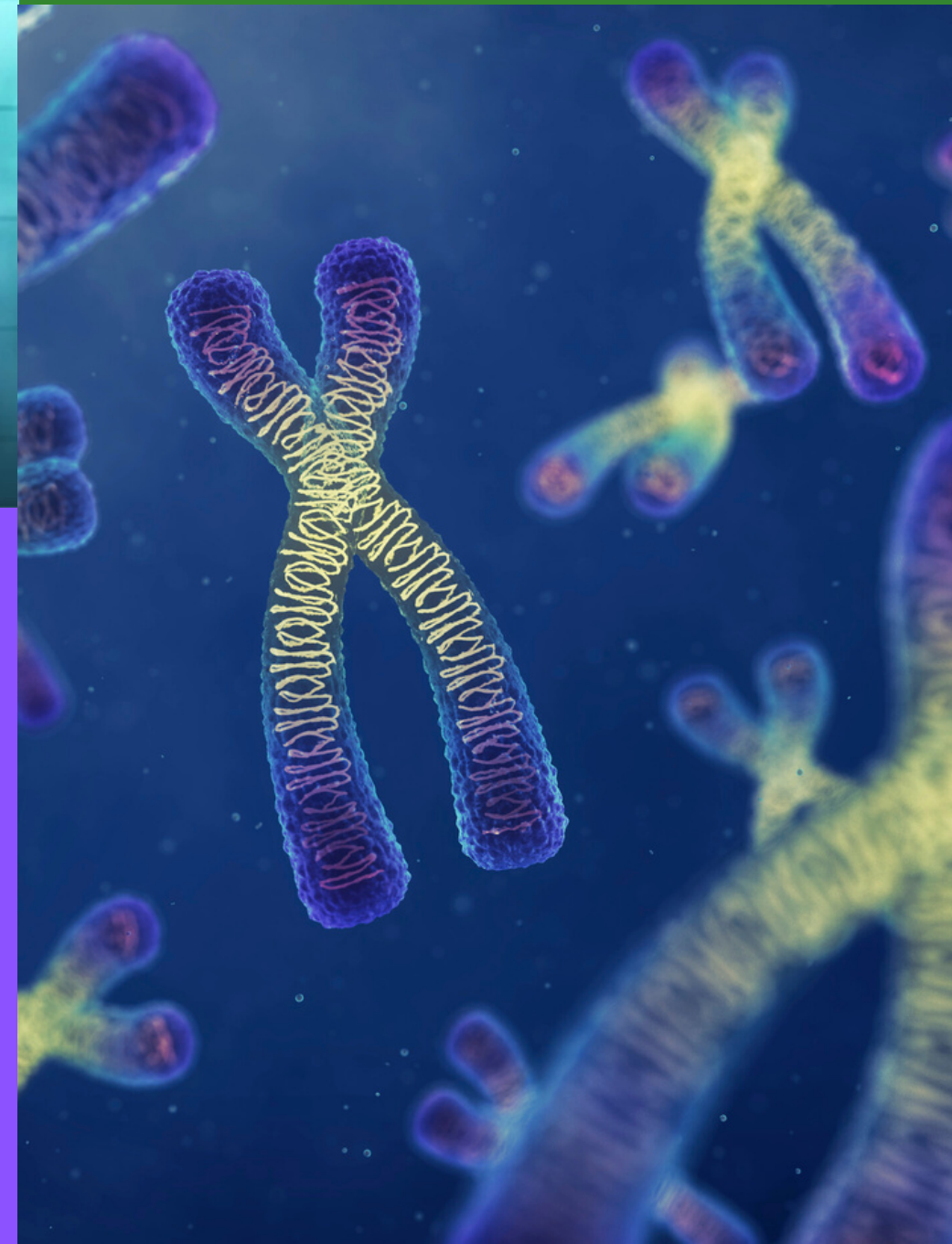
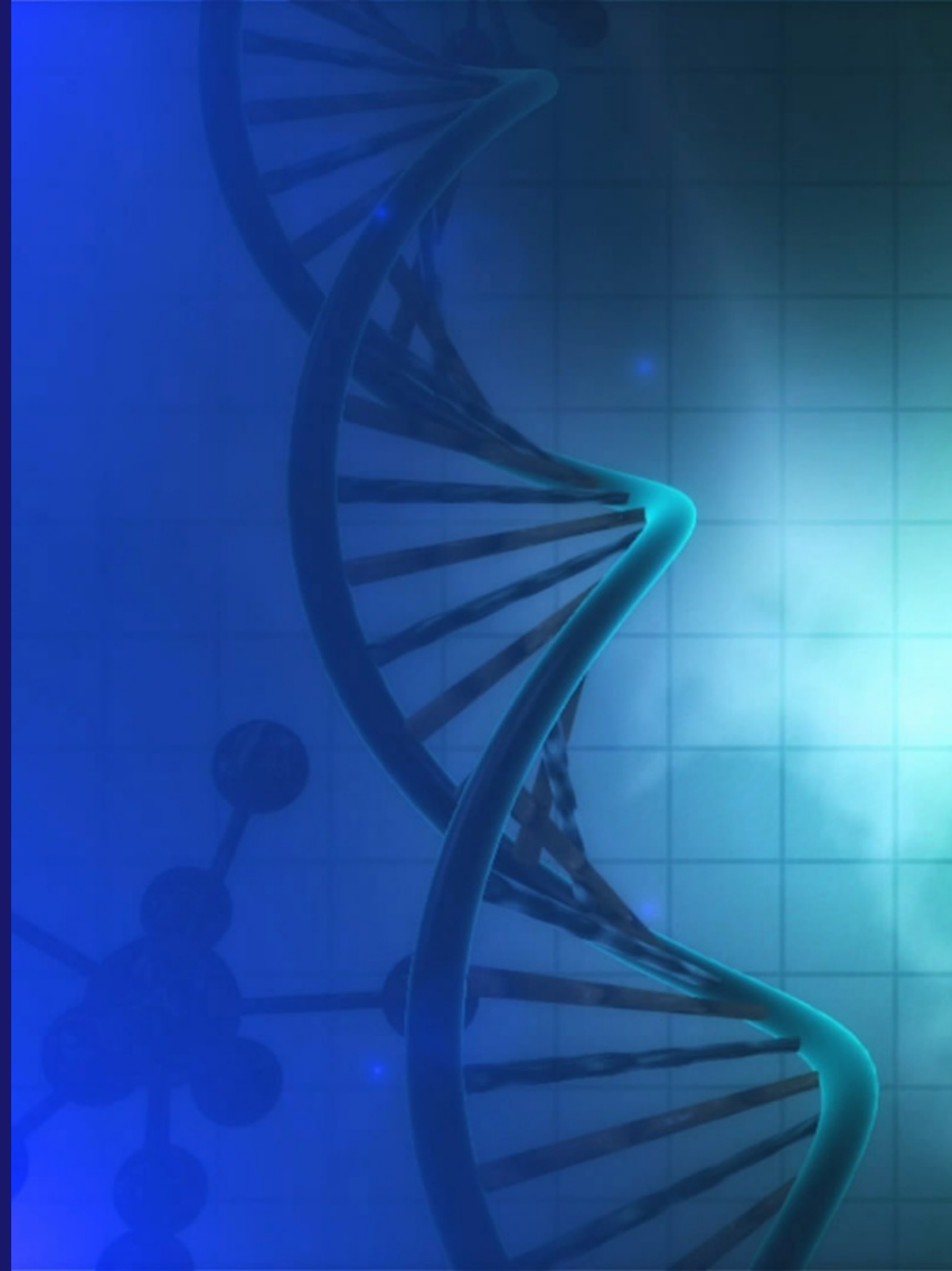
Mountain States Regional Genetics Network



Parent to Parent USA
Leadership Institute
October 19, 2021

Access to
Genetics
Care

Provider
Education,
Family
Education, and
Telegenetics



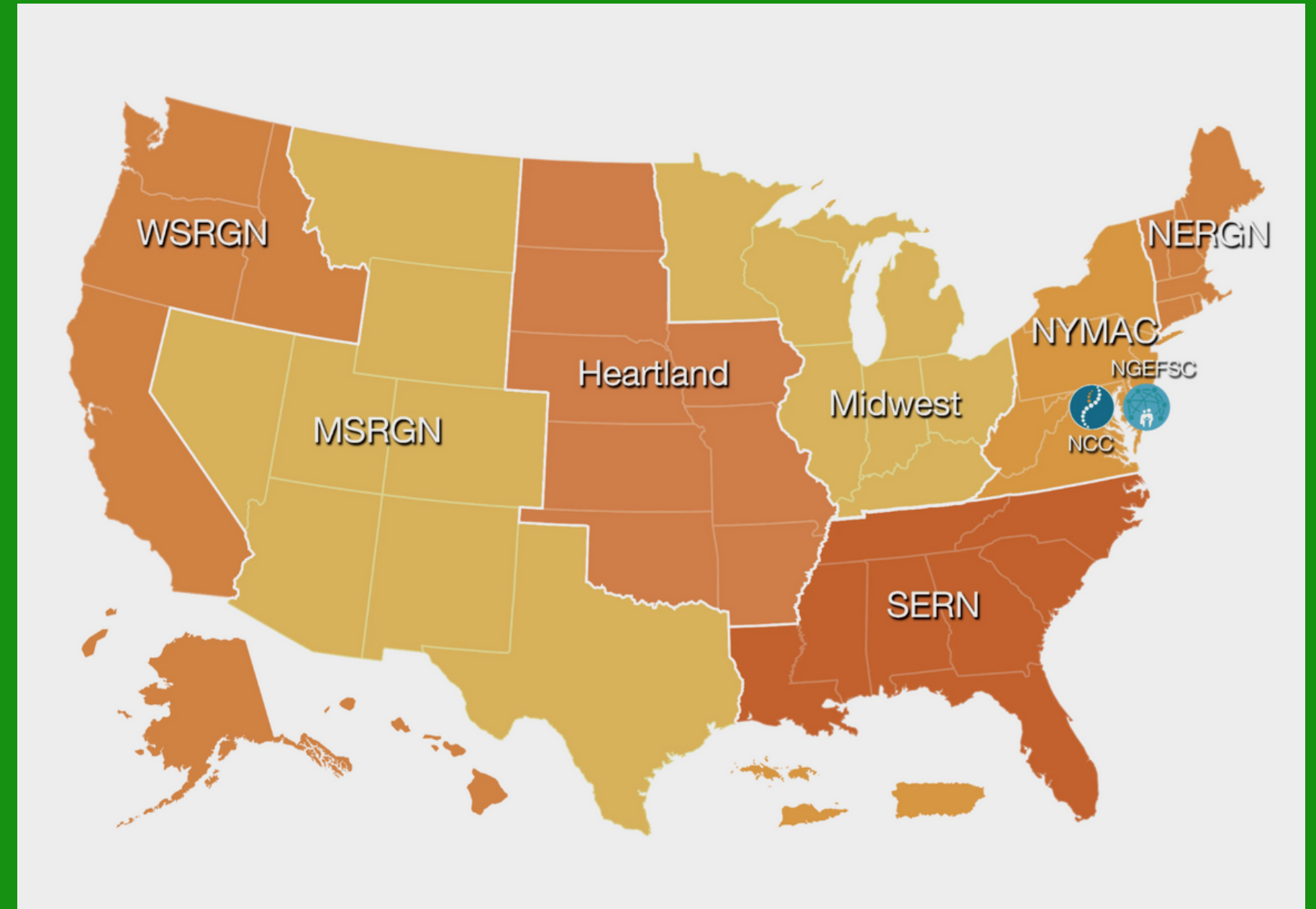
Who is MSRGN?



- MSRGN is an 8-state-regional genetics network
- This network is funded by HRSA (Health Resources Services Administration)
- Funded currently for a 4 year grant cycle from June 1, 2020-May 31, 2024

Part of a National Network

- MSRGN is one of 7 regional genetics networks
- NCC: National Coordinating Center coordinates the work of the network (7 RGNs+NCC+NGEFSC)
- NGEFSC: National Genetics Education and Support Center provides national resources and training to families about genetics



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).



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.**



Program Objectives



Regional Infrastructure

State Teams & Advisory Committee



Education to Providers/Families

Time 4 Genetics

Genetic Ambassadors & Navigators



Telegenetics

Training for Genetic Professionals



Sustainability

Long Term impact



**Kathy Hassell, MD-
Hematologist
Co-Project Director**



**Janet Thomas, MD-
Metabolic Geneticist
Co-Project Director**

MSRGN's Management Team



**Liza Creel-
Evaluator**



**Kristi Wees-
Projects Manager**



**Cody Price-
State Teams Coordinator**

Fudiciary Agent: Texas Health Institute (THI)

This means the HRSA grant funding is awarded to THI and MSRGN is a project under the THI umbrella

Ankit Sanghavi -
Project Administrator
CEO THI

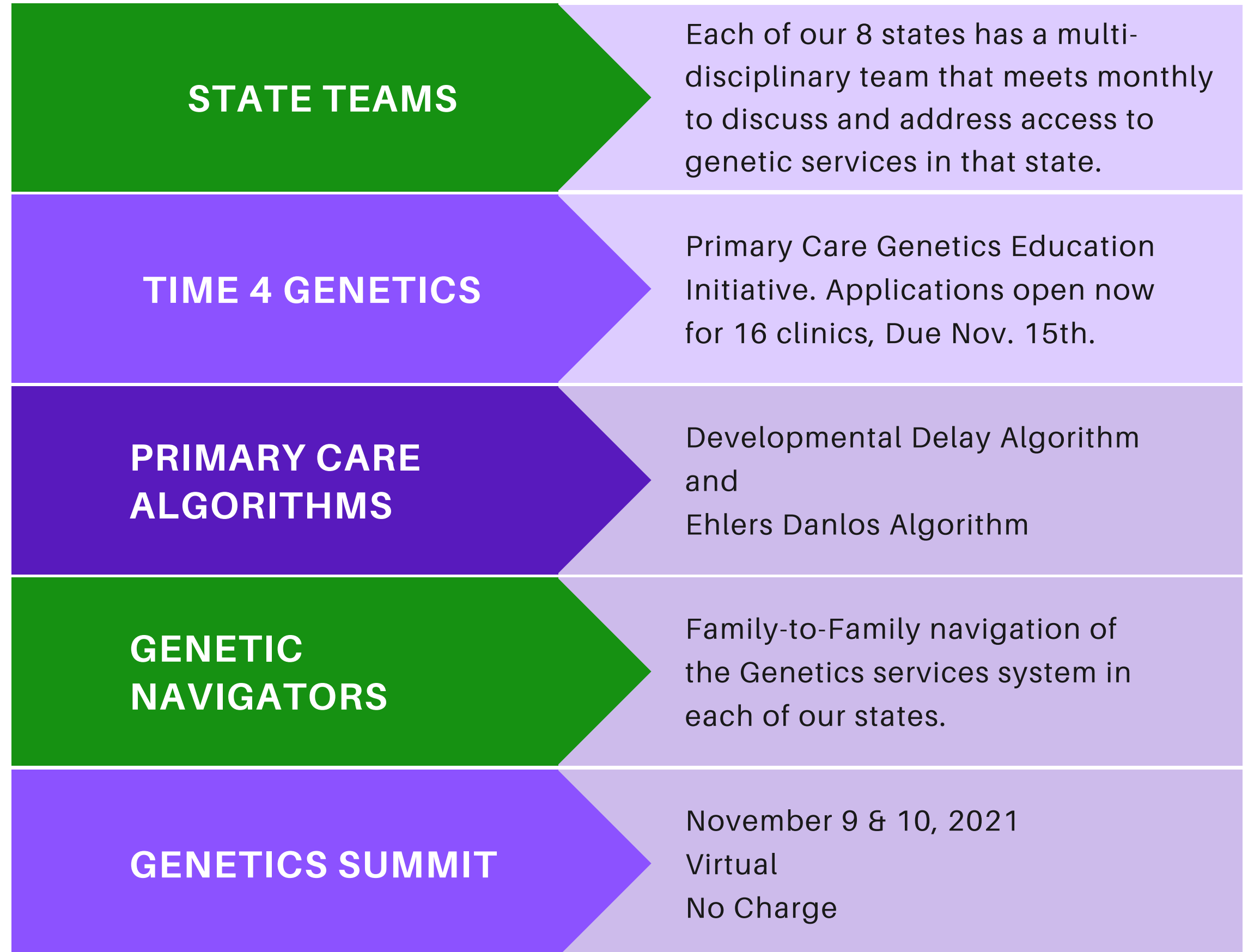
Sherry
Wilkie-Conway-
COO THI

Stephanie Ondrias-
Director Convenings &
Education

Katie Bradley-
Convenings & Education
Coordinator



5 MSRGN Initiatives



MSRGN Initiatives



The Time 4 Genetics goal is to educate, empower and equip 40 primary care/pediatric clinics in our region over the grant cycle. MSRGN will equip these genetic champion primary care clinics with developed newsletters, webinars, mailers and family centered conversations to assist them with genetics in their clinic.

Applications open NOW until November 15th for 16 clinics.

This program has been developed to train and equip state genetic navigators, one per state in our region to help families navigate genetics. This program is stipend funded and includes individuals and families who have experience navigating multiple systems in their state. These individuals also serve on the state team and work closely with the state teams in communicating barriers that families are experiencing in that state as they access genetics care.





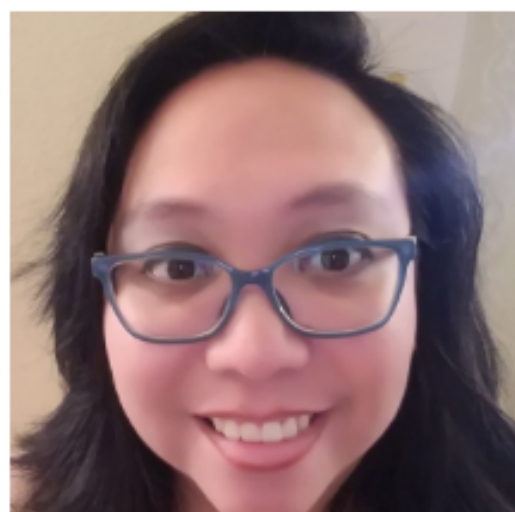
Arizona: Noan



Colorado: Jamie



Montana: Jennifer



Nevada: Hannah



New Mexico: Jennifer



Texas: Lourdes



Utah: Tristin



Wyoming: Melody



states

8

8

navigators

**Meet our
Genetic
Navigators**

Genetic Navigator Role



Family Focused


- **Navigate with professionalism and ethics.**
- **Outreach and engage families who need to navigate genetics in their state.**
- **Guide families as they navigate the genetics system in their state.**
- **Assist in identifying and providing national, regional, state and local genetic resources for families.**
- **Nurture advocacy and growth of family leaders (with-in the family, community, state or nationally).**

For Families with Genetic Concerns a Genetic Navigator can...















- **Discuss next steps with a family and ways they can talk with their doctor.**
- **Connect a family who has received a new genetic diagnosis to support.**
- **Provide resources to a family who has a barrier to accessing genetics services.**
- **Guide families who want to get more involved as an advocate in the genetic service system.**
- **Connect families with other resources such as P2P, state agencies, local, state and national support organizations.**

Red Flags 4 Genetics




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.

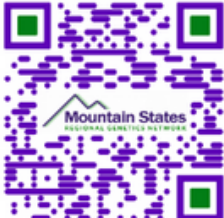
 <div>Developmental Delay</div>		<ul style="list-style-type: none">Physical/motor delay (not rolling over, crawling or walking)Speech (not babbling or responding to name)Adaptive (coordination of hands and fingers)	<ul style="list-style-type: none">Cognitive (unable to or not interested in play)Social/emotional (difficulty interacting with others, not smiling)Loss of any milestone (regression)
 <div>Physical Features</div>	<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)	
 <div>Feeding Issues</div>		<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
 <div>Behavior</div>	<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	
 <div>Failure To Thrive</div>		<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.
 <div>Strength & Tone</div>	<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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Open to Families and Family Leaders!

Our 2021 Genetics Summit is planned virtually for
November 9-10, 2021

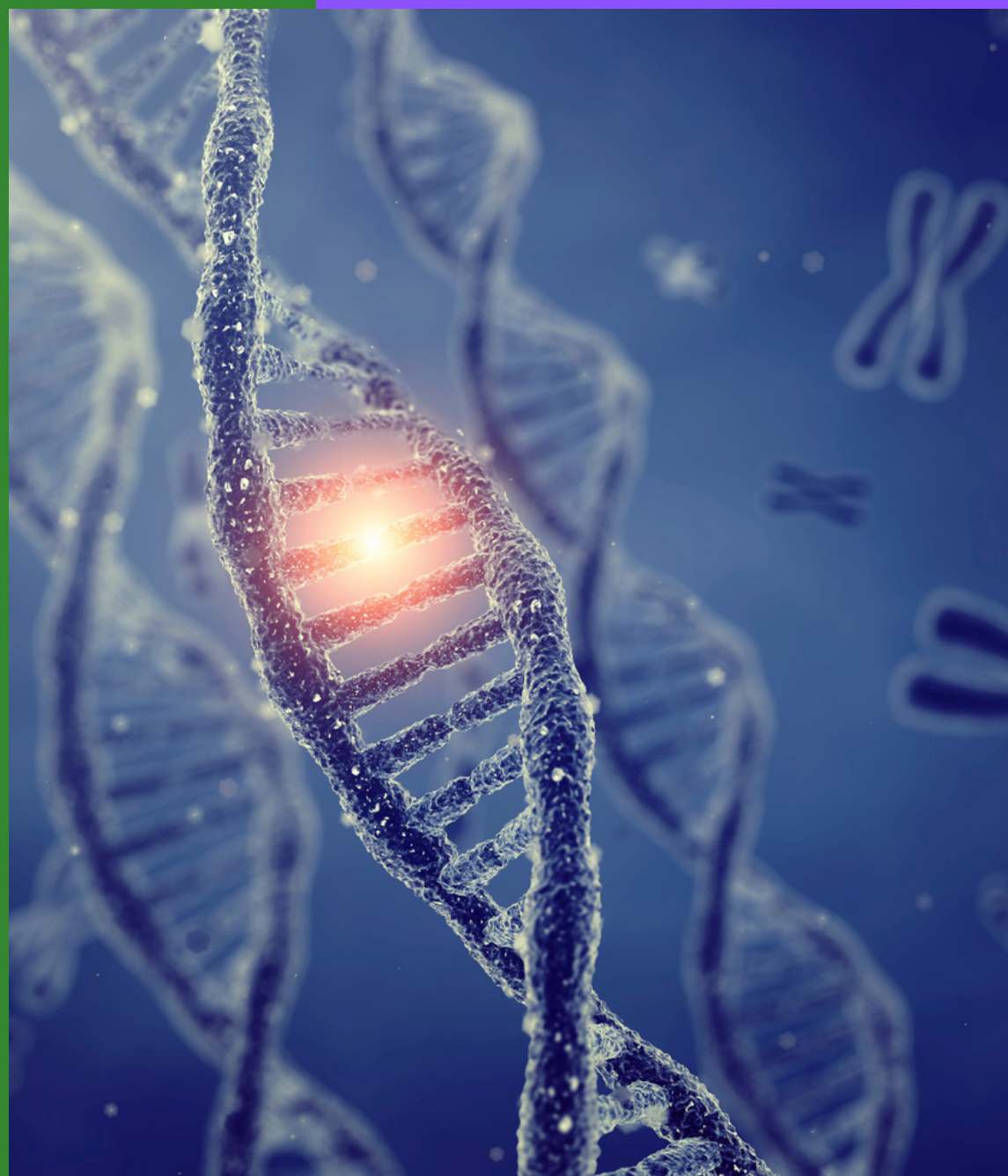
No charge- open to all!

Registration available NOW!

www.mountainstatesgenetics.org/GS2021

MSRGN
GENETICS SUMMIT 2021
CONNECTING
THE DOTS
November 9-10, 2021





Thank you!

Any additional Questions for us?

Website: www.MountainStatesGenetics.org

To contact MSRGN's Project Manager,

Kristi Wees:

kwees@mountainstatesgenetics.org



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