

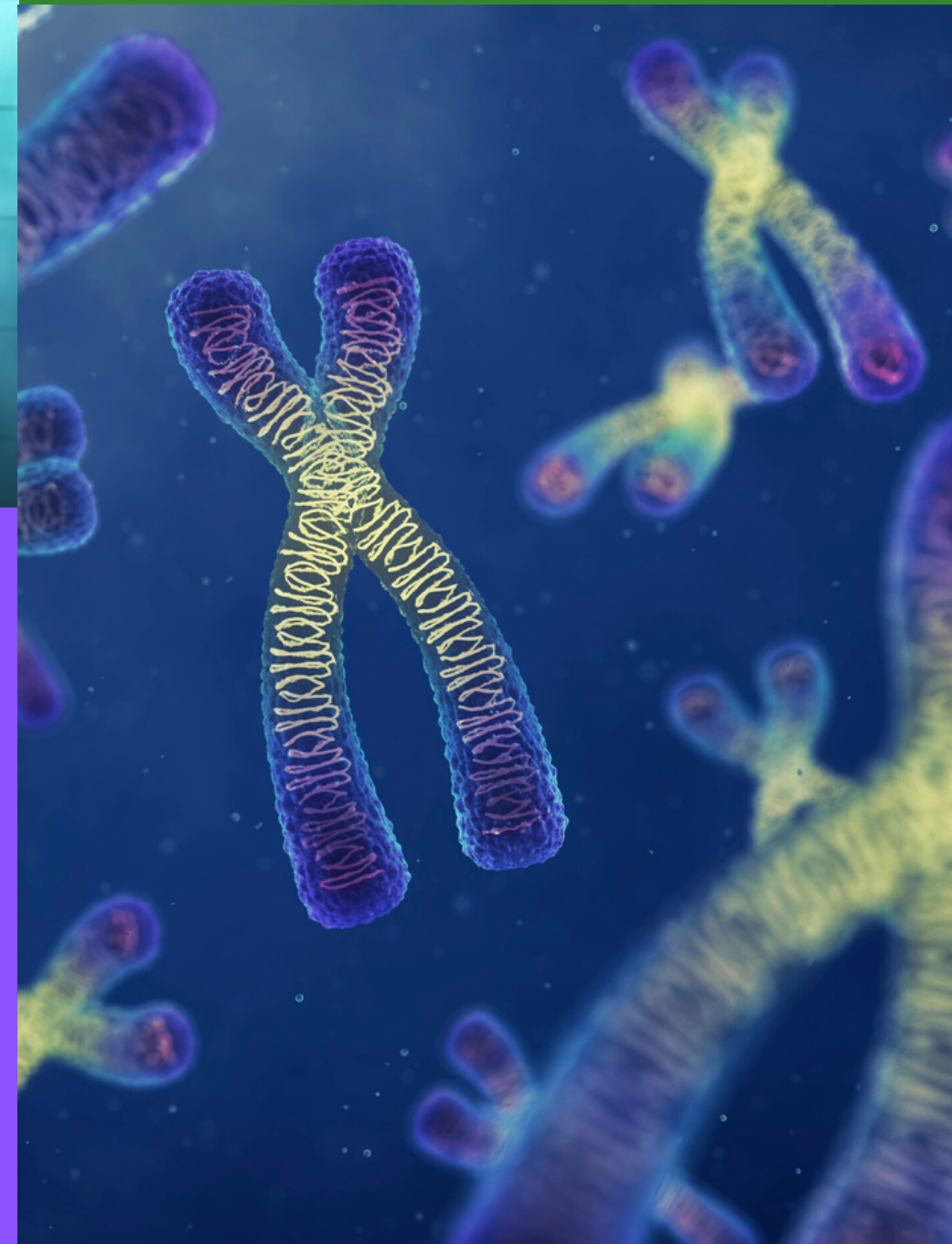
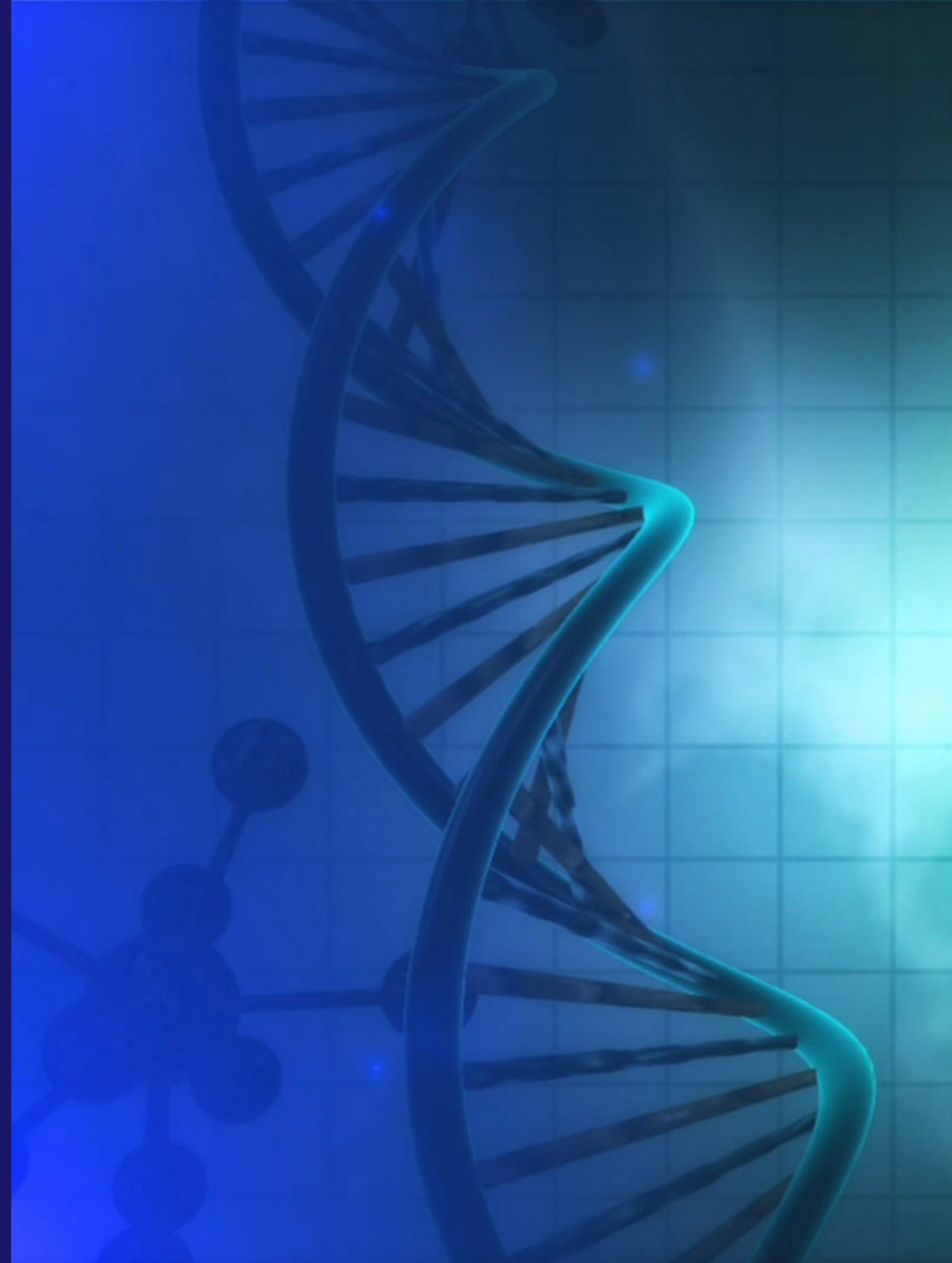
MSRGN 2020-2024



Genetic Navigator
Outreach
2023-2024

Access to
Genetics
Care

Provider
Education,
Family
Education, and
Telegenetics



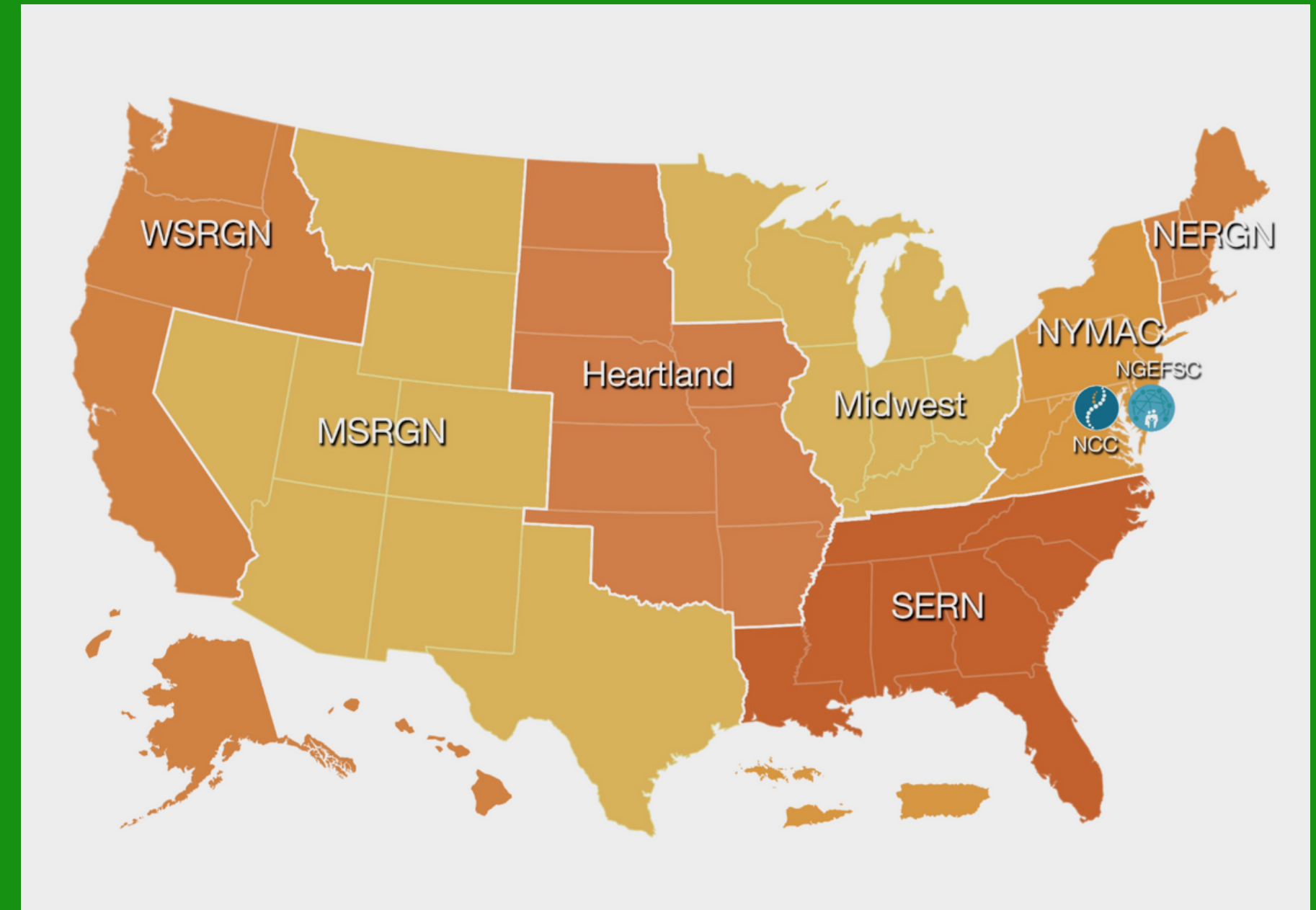
Who is MSRGN?



- 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 networks (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).

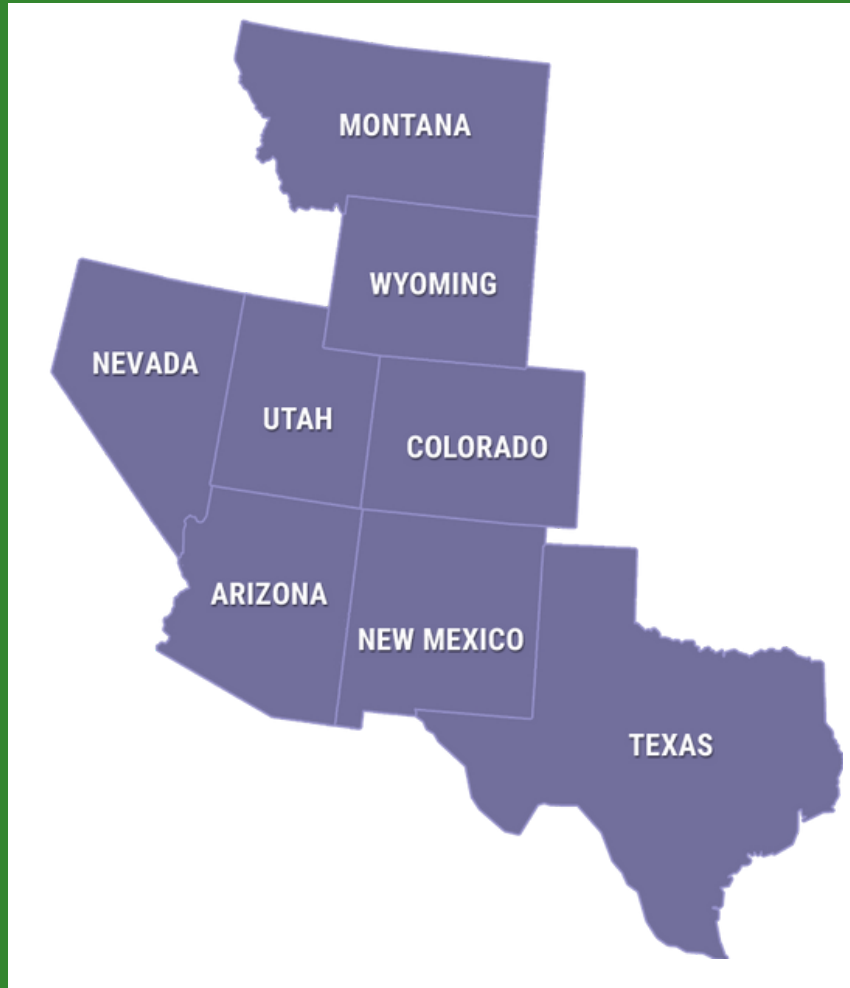


MSRGN's Mission:

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

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

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Project Administrator
CEO THI

Sherry
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COO THI

Stephanie Ondrias-
Director Convenings &
Education

Katie Bradley-
Convenings & Education
Coordinator





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

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



MSRGN's Management Team



**Liza Creel-
Evaluator**



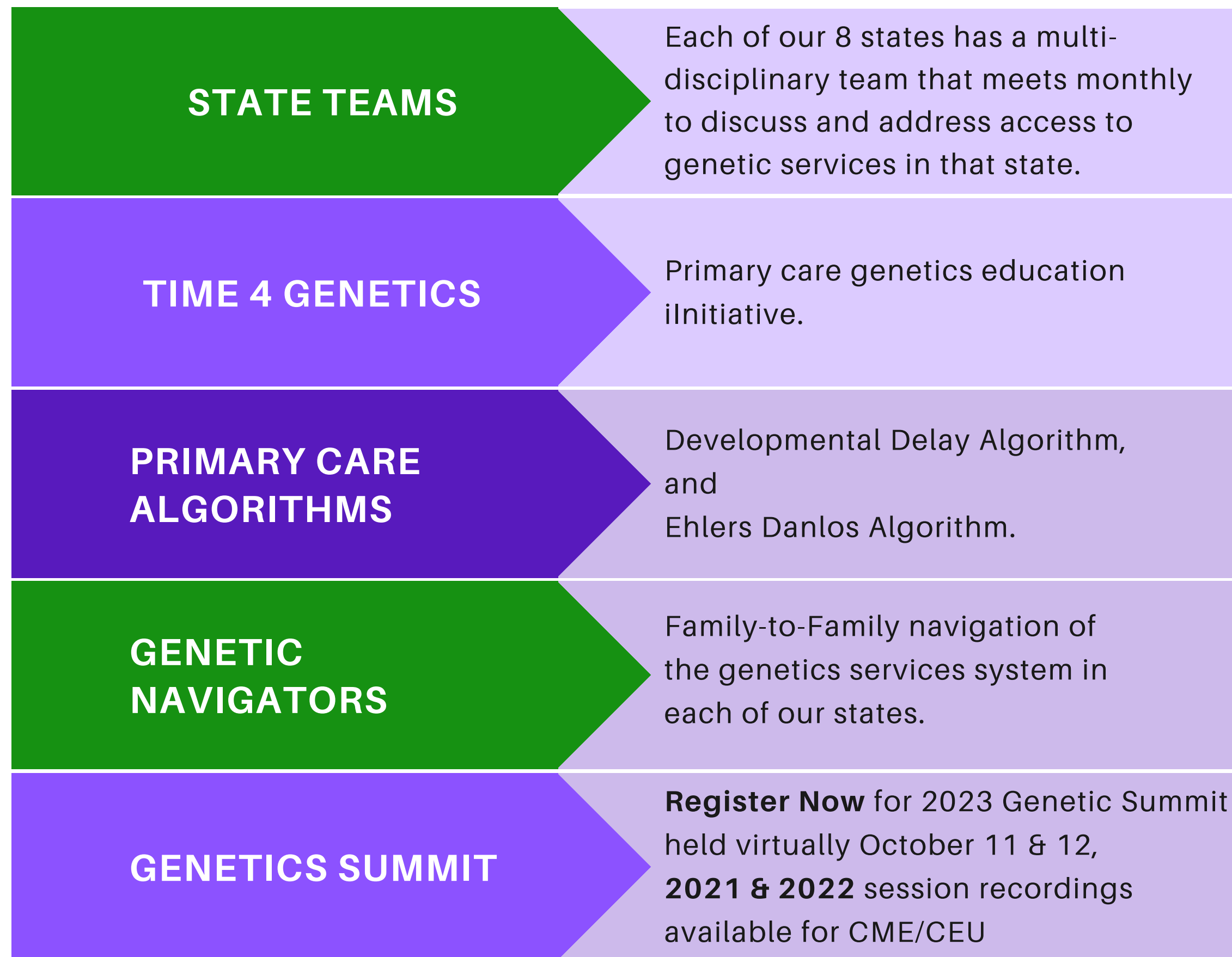
**Mikayla Welch-
Project Coordinator**



**Kristi Wees-
Projects Manager**



5 INITIATIVES





Arizona: Noan



Colorado: Jamie



Montana: Jennifer



Nevada: Mariah



New Mexico: Desirée



Texas: Lourdes



Utah: Tiffany



Wyoming: Kala



GENETIC
NAVIGATORS

states

8

8

navigators

**Meet our
Genetic
Navigators**

Genetic Navigator Role

Family Focused



How I Can Help a Family Navigate Genetics...

- Discuss next steps with a family who has concerns, for example, ways they can talk with their doctor.
- Provide resources to a family who has encountered a barrier to accessing genetic services.
- Connect families who have received a genetic diagnosis to support organizations.
- Meet with families who want to get more involved as an advocate in the genetic system.

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.

Developmental Delay



- Physical/motor delay (not rolling over, crawling or walking)
- Speech (not babbling or responding to name)
- Adaptive (coordination of hands and fingers)
- Cognitive (unable to or not interested in play)
- Social/emotional (difficulty interacting with others, not smiling)
- Loss of any milestone (regression)

Physical Features

- Extra fingers or toes
- Large/small head size (macrocephaly/microcephaly)
- Short/tall height (stature)
- Cleft palate
- Facial feature differences (small chin, wide forehead)
- Frequent joint dislocations (hip dysplasia)
- Spinal deformities (scoliosis)



Feeding Issues



- Difficulty swallowing
- Struggles with breastfeeding
- Poor latching
- Feeding tube dependent
- Never feeling full
- Poor appetite
- Vomiting
- Gagging on food

Behavior

- Autism Spectrum Disorder (ASD)
- Repetitive movements
- Constantly upset or crying
- Lack of eye contact
- Difficulty in school or social settings
- ADHD/impulsive or hyperactive behavior
- Easily distracted
- High pitched cry/tone of voice



Failure To Thrive



- Slow growth
- Slow weight gain
- Not thriving
- Fatigues quickly when active
- Weight or rate of weight gain being much lower than that of other children.

Strength & Tone

- 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
- Muscle weakness
- Body is floppy
- Inability to lift or control head (head lag)

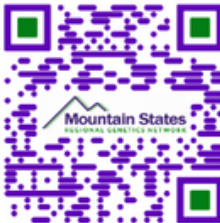


Other Red Flags

- Seizures
- Sleep concerns
- Fatigue
- Lethargy
- Hearing/vision concerns
- Immune issues
- Headaches/migraines
- Neurological concerns
- Pulmonary/cardiac concerns
- GI issues (reflux/bowel concerns)
- Bruising

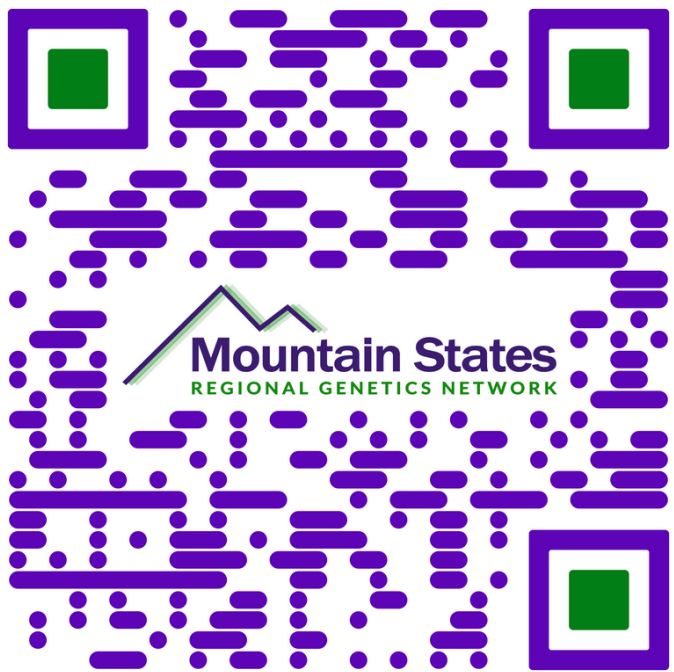


If your child is exhibiting any **'red flags'** on this page please talk to your child's pediatrician or primary care physician. For more resources and help having that conversation, go to:
www.mountainstatesgenetics.org/redflag



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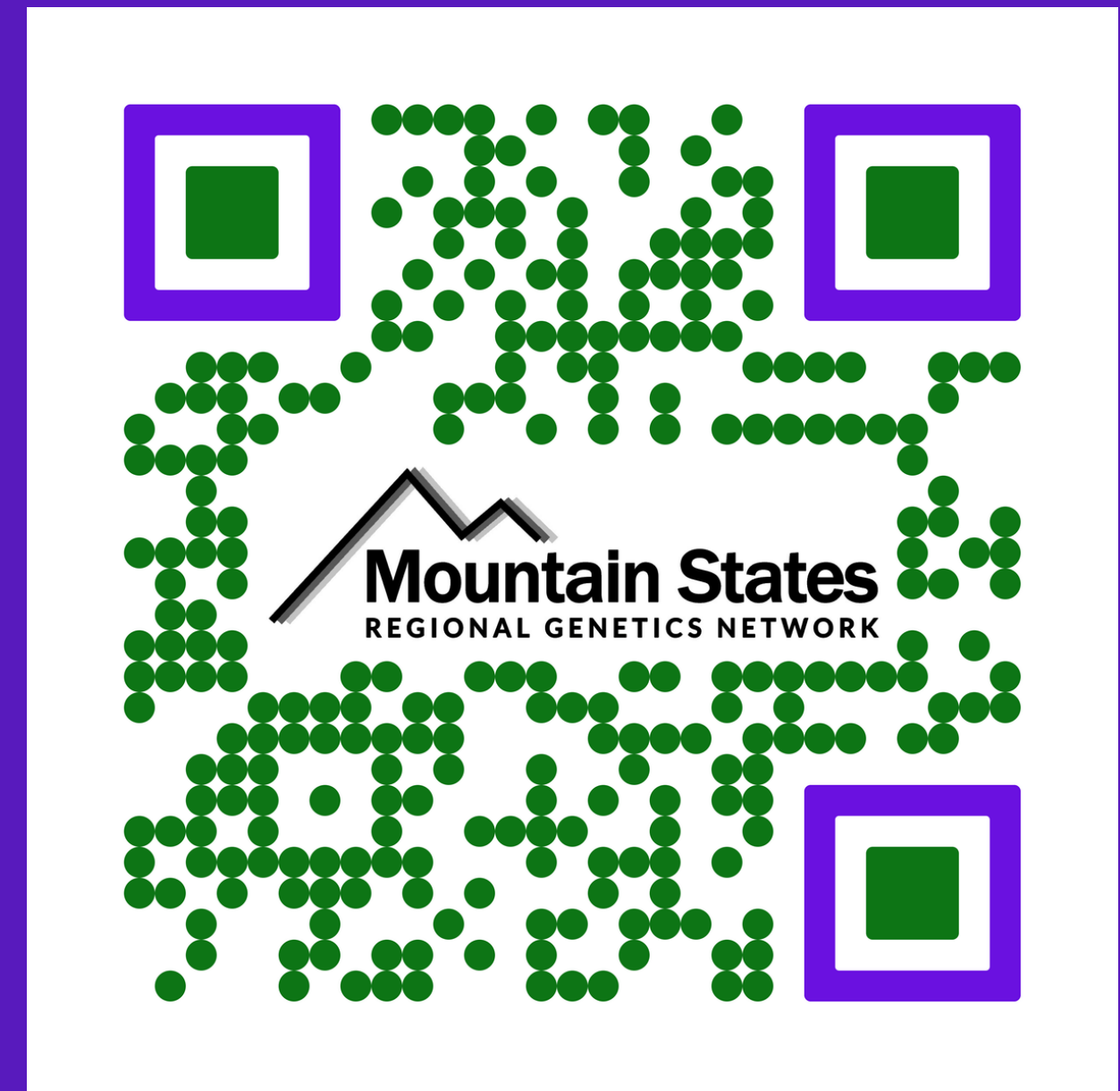
Available in
English &
Spanish



www.mountainstatesgenetics.org/redflagnews/



Genetic Summit Library



Time 4 Genetics

Pediatric Genetics Education for the Primary Care Clinic

Time 4 Genetics Library

Red Flags

Developmental Delays

EDS

Genetic Testing

Autism

Cerebral Palsy

Newborn Screening



Seizures



<https://www.mountainstatesgenetics.org/t4glibrary/>


Time 4 Genetics

our LAST Webinar




JOIN US FOR THE TIME 4 GENETICS WEBINAR:


**ARE ALL VARIANTS OF
UNCERTAIN SIGNIFICANCE
CREATED EQUAL?
A ROUGH GUIDE**



January 29, 2024
(at 11am PT, noon MT, 1pm CT, and 2pm ET)



Guest Presenters:
Dr. Abdallah (Abe) Elias
Clinical Geneticist, Medical
Director of the Department of
Medical Genetics at Shodair
Children's Hospital
&
Jaclyn Haven, MS, CGC
Genetic Counselor,
Chief Administrative Officer of
Medial Genetics
Department of Medical Genetics at
Shodair Children's Hospital



[https://www.mountainstatesgenetics.org/time-4-genetics-webinar-variants-of-uncertain-](https://www.mountainstatesgenetics.org/time-4-genetics-webinar-variants-of-uncertain-significance-when-created-equal/)



Navigating to Hope

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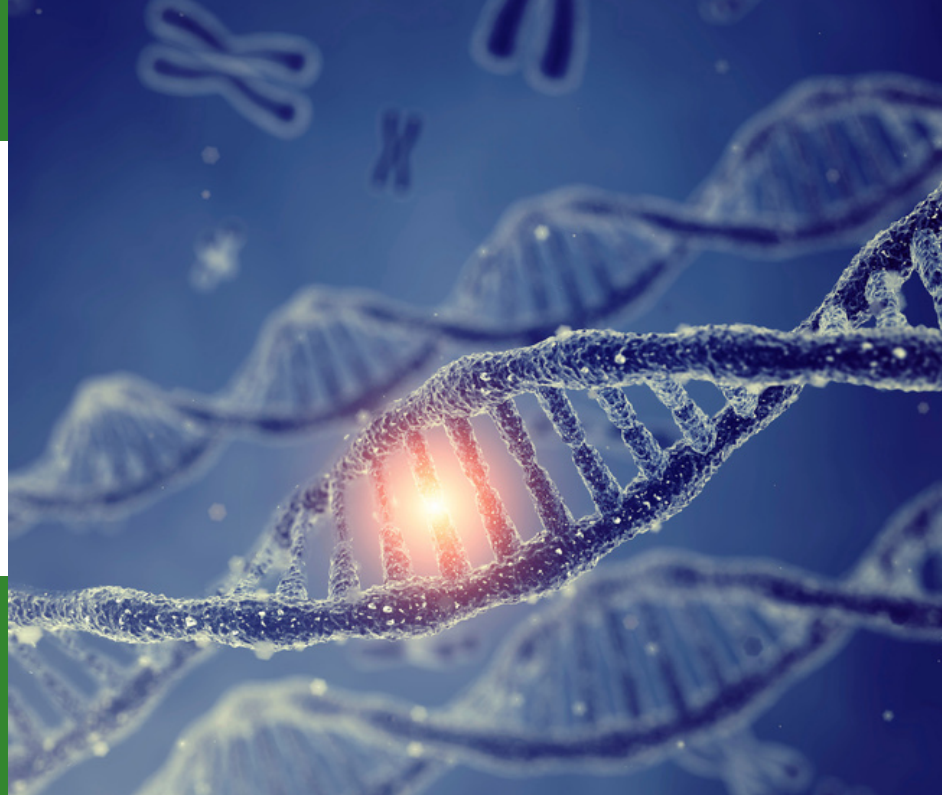
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Thank you!

Any additional Questions for us?

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