HRSA Overview
Heartland Regional Genetics Network Annual Meeting

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Maternal and Child Health Bureau (MCHB)

Vision: Healthy Communities, Healthy People
Health Resources and Services Administration

HRSA’s Mission:
To improve health outcomes and address health disparities through access to quality services, a skilled health workforce, and innovative, high-value programs.

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Maternal and Child Health Bureau

Mission:
Improve the health of America’s mothers, children, and families.
Paradigm for Improving Maternal and Child Health

Accelerate
Upstream
Together
Today’s Maternal and Child Health Bureau

MCHB Program Areas

- State & Community Health
- Home Visiting & Early Childhood Services
- Healthy Start & Perinatal Services
- Child, Adolescent and Family Health
- MCH Workforce Development
- Epidemiology & Research
- Services for Children with Special Healthcare Needs
Division of Services for Children with Special Health Needs

DSCSHN Mission
To provide national leadership to expand and strengthen access to a system of services for CYSHCN and their families as they grow and transition through adulthood.

Who do we serve?
Children or youth who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services or a type or amount beyond that required for children generally.
Six Indicators of a Well-Functioning System

- Individuals & Families
  - Families as partners
  - Medical home
  - Adequate insurance
  - Early and continuous screening
  - Transition to adulthood
  - Community-based services

Family centered care

Cultural & linguistic competence
DSCSHN: Program Snapshot

Systems of Care
- Medical home
- Transition
- Financing
- Family/Professional Partnership
- CSHCN Research Network
- CMC CoLLIN

Screening
- Newborn screening
- Genetics Programs
- Vision
- Early Hearing Detection and Intervention
- Environmental Health

Condition-specific
- Epilepsy
- Autism
- Hemoglobinopathies
- Hemophilia
Genetics Programs

Overarching Goal
To improve access to genetic services, especially for underserved, disadvantaged, geographically isolated, and special needs populations.
Genetics Programs Priorities

- Improved system of coordinated and comprehensive genetics services
- Educational resources for primary care and non-genetics providers
- Family Engagement and Leadership
- National policies, evidence-based practices, and resources
- Telegenetics
- Educational resources for families
- Outreach to Underserved Population
- Provide TA and support to RGNs
- Expanding regional Infrastructure

Programs and Initiatives:
- Regional Genetics Networks (HRSA-20-046)
- Advances in Integrating Genetics into Clinical Care (HRSA-20-050)
- National Genetics Education and Family Support Program (HRSA-20-049)
Support a regional infrastructure for the genetics health care delivery system

- Strengthen, build, and expand partnerships, relationship, and infrastructure throughout each state of the region
- Develop and implement mechanisms to identify individuals and their families with or at risk for genetic disorders, especially underserved, and connect them to genetic services
Regional Genetics Networks Priorities 2020-2024

Provide education-related activities for providers, families, individuals, and other stakeholders.

- Develop and expand educational resources for health professionals
- Develop educational resources for families and support to family leaders to participate in MSRGN and genetics care delivery system

Facilitate the use of telehealth and telemedicine in the genetics health care delivery system.

- Provide technical assistance, training, and support to providers on telehealth
- Facilitate implementation and expansion of telehealth in genetics service provision
What and why do we measure?

• RGN Program Objectives 2020-2024
  ▪ Each RGN will facilitate connections to genetic services for at least 2,000 individuals or families with or at risk for genetic conditions, within the geographic area served by the RGN.
  ▪ Increase to at least 33% of the individuals who are medically underserved with or at risk for genetic conditions, served by each RGN.
  ▪ Increase by 20% the number of health care providers receiving education or training through the RGN.
  ▪ Increase by 20% the number of individuals with or at risk for genetic conditions, receiving genetic services through telemedicine visits.
  ▪ Increase by 20% the number of RGN resources accessed.

• Program Measures

• Progress Reports – Both Quantitative and Qualitative
New Websites

• **Newbornscreening.hrsa.gov**
  - Provides clear and up-to-date information, materials, and resources about NBS in the United States. These resources help increase awareness, knowledge, and understanding of NBS and genetic conditions.

• **Telehealth.hhs.gov**
  - Provides information for patients and providers about the latest federal efforts to support and promote telehealth services
Mark your calendar

• Next meeting scheduled for May 13-14, 2021  Register Here
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