



# The Heartland RC

## Regional Genetic and Newborn Screening Service Collaboratives

Michele A. Lloyd-Puryear, M.D., Ph.D.  
Chief, Genetic Services Branch

Jill F. Shuger, M.S., Project Officer

Health Resources And Services Administration  
Maternal And Child Health Bureau  
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# The Health Resources and Services Administration (HRSA)

HRSA is the Nation's access agency –improving health and saving lives by making sure the right services are available in the right places at the right time.

- Vision: HRSA envisions optimal health for all, supported by a health care system that assures access to comprehensive culturally competent, quality care.
- Mission: HRSA provides national leadership, program resources and services needed to improve access to culturally competent, quality health care.

# Heritable Disorders Program

## Converging Events Led to Program Development

- The PRINCIPLE that “effective newborn screening (NBS) systems are available for all children in the United States”
- Initially stated by the American Academy of Pediatrics (AAP) convened Newborn Screening Task Force, May 1999, D.C.
- Publication: *Serving the Family From Birth to the Medical Home – A Report From the Newborn Screening Task Force Convened in Washington, D.C., May 10-11, 1999* (2000).



# Heritable Disorders Program

## A Rapidly Expanding and Changing Landscape of Genetic and Newborn Screening Services

- Advanced NBS technology and the challenges in implementing those services.
- States and local public health agencies needed to mobilize to enhance, expand and improve NBS services for children at risk, including increase access to underserved families.
- States had to develop infrastructure to support NBS Programs.
- There was increased need for subspecialists and “super” subspecialists to care for individuals identified through genetic testing as having rare disorders.
- The geographic maldistribution of genetic and medical subspecialist expertise throughout the country was recognized.



# Heritable Disorders Program

HRSA-commissioned American College of Medical Genetics Report on newborn screening would be forthcoming (2004-2006).

- Recommended expanding NBS services.
- Exacerbating issues around access and maldistribution of genetic services providers.
- Findings, *Newborn Screening: Toward a Uniform Screening Panel and System*, Genetics in Medicine, May 2006, vol. 8, No. 5.
- Visit the website: <http://www.acmg.net>.



# Heritable Disorders Program

## Rationale for Initiative

- These are issues best addressed by combining national, regional and local approaches.
- A network of regional centers was selected to:
  - Bring genetic and NBS services to local communities by sharing expertise and resources.
  - Facilitate collaboration between public health (NBS), primary care, and subspecialist providers.
  - Capitalize on existing interstate NBS laboratory and surveillance program relationships.



# Heritable Disorders Program

- Established under Title XXVI of the Children's Health Care Act of 2000 "Screening for Heritable Disorders"
  - Advisory Committee to the Secretary
    - Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children.
    - Visit the Website:  
<http://mchb.hrsa.gov/programs/genetics/committee/default.htm>
  - Grant Program
    - National Coordinating Center
    - 7 Regional Collaboratives
    - Visit the Website: <http://nncrcg.org>



# Heritable Disorders Program

## Legislation

“....The Secretary shall award grants to eligible entities to enhance, improve or expand the ability of State and local public health agencies to provide screening, counseling or health care services to newborns and children having or at risk for heritable disorders...”



# Heritable Disorders Program

- Provide screening, counseling, testing or specialty services.
- Reduce mortality and morbidity.
- Provide information and counseling on available therapies.
- Improve access of medically underserved populations to services.

# Regional Genetic and Newborn Screening Service Collaboratives



## Response

- In 2004, Congress appropriated funds to implement the priorities of the Program.
- Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA):
  - 7 Regional Genetic and Newborn Screening Service Collaboratives (RC)
    - Groups of adjoining states with similar overall birthrates;
    - And shared programmatic histories.
  - A National Coordinating Center
    - Housed At the American College of Medical Genetics



# Regional Genetics and Newborn Screening Service Collaboratives

## 5 Year Grant Award

- Project Period: 06/01/07 – 5/31/12
- RC Base Funding
- RC Additional Priority Activities
  - Laboratory Performance Priority Activity 1
  - LTFU Priority Activity 2
- Cooperative Agreement
- Visit the Website:  
<http://www.nccrcg.org>.



# Regional Genetics and Newborn Screening Service Collaboratives

## RC Base Funding

### Seven (7) Regional Collaboratives Their States and Territories

- Region 1. New England RC - CT, MA, ME, NH, RI, & VT.
- Region 2. NY/Mid-Atlantic RC - DC, DE, MD, NY, NJ, PA, VA, WV.
- Region 3. Southeastern RC - AL, FL, GA, LA, MS, NC, PR, SC, TN, VI.
- Region 4. Great Lakes RC - IL, IN, KY, MI, MN, OH, WI.
- Region 5. Heartland RC - AR, IA, KS, MO, ND, NE, OK, SD.
- Region 6. Mountain States RC - AZ, CO, MT, NM, NV, TX, UT, WY.
- Region 7. Western States RC - AK, CA, HI, ID, OR, WA, Guam.



# Regional Genetics and Newborn Screening Service Collaboratives

## RC Primary Goal

- Ensure that children with heritable disorders and their families have access to quality care and appropriate genetic expertise and information in the context of a medical home that provides accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective care.

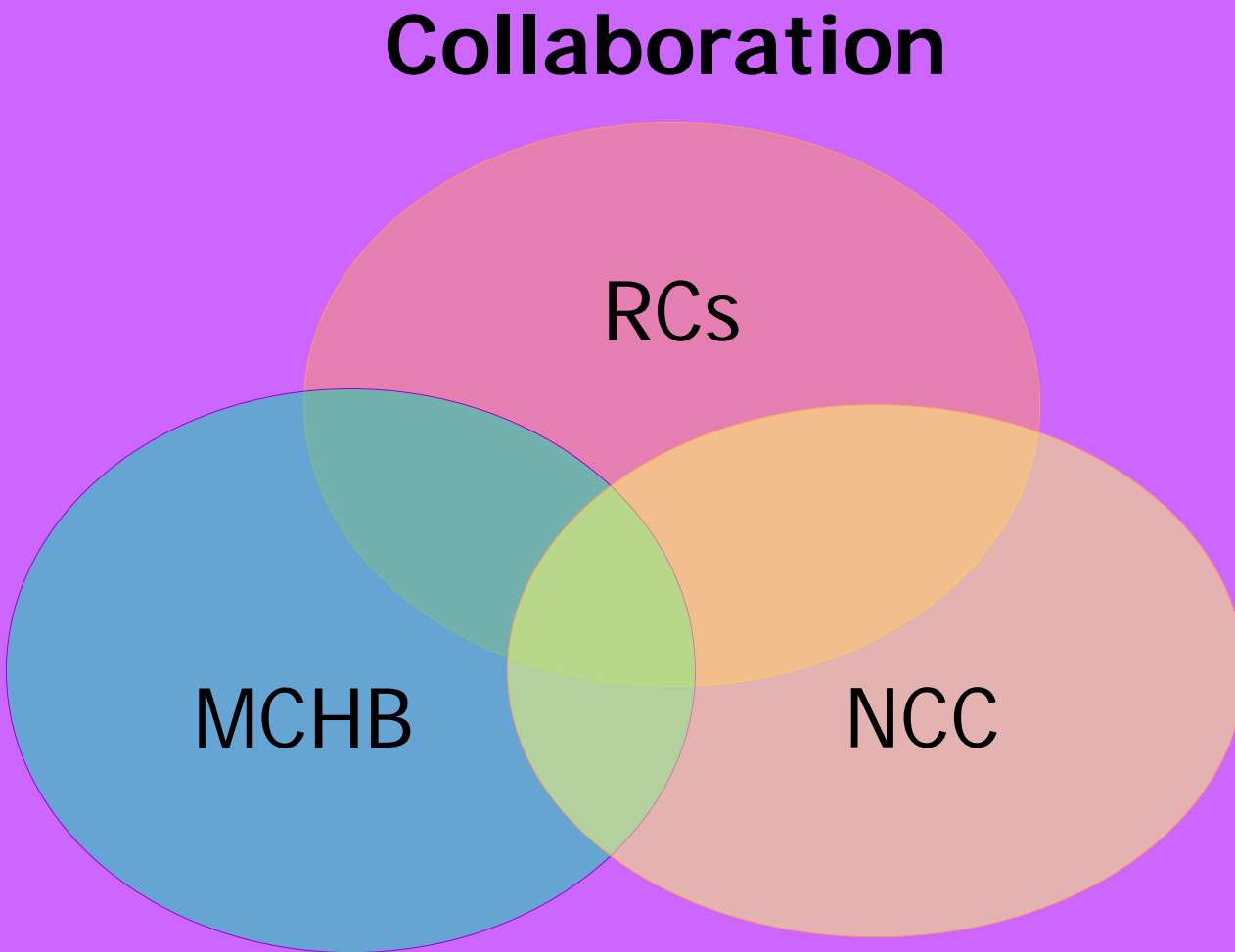


# Regional Genetics and Newborn Screening Service Collaboratives

## RC Two Objectives

- To strengthen communication and collaboration among public health, individuals, families, primary care providers, and genetic medicine and other subspecialty providers.
- To quantitatively and qualitatively evaluate outcomes of projects undertaken to accomplish their goals.

# Regional Genetics and Newborn Screening Service Collaboratives



Health Resources and Services Administration

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# Regional Genetics and Newborn Screening Service Collaboratives

## Laboratory Quality Assurance Priority Activity 1

- NBS public health laboratory quality-improvement projects such as enhancing NBS analytical laboratory test performance across the country and focusing on existing technologies currently in use in State NBS programs such as tandem mass spectrometry.
- Primary outcomes should be - harmonization of case definitions of disorders screened in NBS programs, NBS panels, and testing methodologies and decreasing the number of false positives.
- **HRSA MCHB Priority Activities**
  - **Region 4 Great Lakes RC**
  - **Southeastern RC**
  - **New England RC**
  - **Mountain States RC**

# Regional Genetics and Newborn Screening Service Collaboratives



## Follow-up Priority Activity 2

- Participate in collaborative study and health information technology and information exchange activities including the creation and use of regional and national information systems designed to: monitor health outcomes of infants and children identified with heritable disorders in NBS programs; evaluate NBS performance; and evaluate treatment protocols.
  
- Reflect collaborative activities between the public health NBS program and the service delivery system. Build on existing child health information systems activities in the region. Address issues of informed consent and family acceptance of screening and treatment.
  
- **HRSA MCHB Funded Priority Activities**
  - **Region 4 Great Lakes RC**
  - **Southeastern RC**
  - **New England RC**



# Regional Genetics and Newborn Screening Service Collaboratives

## **VISION – Or where I want to be in 5 years!**

- All Health care and public health professionals will have genetic resources at their fingertips and will understand what it means to “think genetically”.
- The general public will know that the regional collaborative is the “go to place” for information about genetic resources and services within the region.



# Contact Information

**Thank You!**

**Jill F. Shuger, M.S.  
Genetic Services Branch  
HRSA/Maternal and Child Health Bureau  
5600 Fishers Lane, Room 18A-19  
Rockville, MD 20857  
Ph: 301.443.3247  
Fax: 301.443.8604  
E-mail: [jshuger@hrsa.gov](mailto:jshuger@hrsa.gov)**