



# National and Cross-Regional Projects

from the

## National Coordinating Center for the Regional Genetic and Newborn Screening Services Collaboratives (NCC)

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# NCC and the 7 HRSA Genetics Collaboratives





# Overarching Goals of the NCC

## All NCC activities work toward:

- Building bridges between public health, primary care/medical home, geneticists/specialists, patients/families and MCHB;
  - Facilitating the movement of quality genetic and NBS services to local communities; and
  - Enhancing the activities of the seven RCs by providing the infrastructure, coordination, technical assistance and resources necessary to address issues of universal importance, thereby avoiding duplication of efforts and allowing the regions to focus on their unique areas of need.
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# NCC Workgroup Initiatives

- ◆ **ACT Sheets**
  - ◆ **Evaluation**
  - ◆ **Long-Term Follow-Up**
  - ◆ **Medical Home**
  - ◆ **Publications**
  - ◆ **Telemedicine**
  - ◆ **Transition**
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# Bringing National Issues to the Local Level

- ◆ **Information sharing on emerging topics:**
    - Health Care Reform and Financing
    - Health Insurance
    - Workforce Development
  
  - ◆ **Collaboration with National Centers:**
    - National Center for Medical Home
    - National Coordinating and Evaluation Center for Sickle Cell Disease and Newborn Screening
    - National Health Care Transition Center
    - Data Resource Center for Child and Adolescent Health
    - National Center for Family/Professional Partnerships
    - Catalyst Center
    - Information Clearinghouse
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# National Projects-Education and Training

- **ACT Sheets**

Clinical decision support tools developed to provide to primary care providers information around disorders on the newborn screening panel.

- **Genetics & Medical Home Visiting Professorships**

Enhance medical home education for providers and families within the RCs and expand genetics/nbs related educational opportunities for primary care providers.

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# National Projects-Education and Training

- ◆ **NCC Collaborator**
  - Quarterly themed issue showcasing NCC, RC, & partner activities
- ◆ **Hearing Loss Brochure**
  - Parent resource highlighting importance of genetics
- ◆ **Cultural Competence**
  - Native American Perspectives
  - CPT1A Screening in First Nations





# National Projects-Follow-Up and Treatment

## ◆ NCC Long-term follow-up Supplement:

Goal	Deliverable
Coordinate and accelerate LTFU efforts	<ul style="list-style-type: none"><li>• Engage RCs</li><li>• Define barriers to LTFU</li><li>• Work with Effective Follow-up Grantees</li><li>• Complete state survey</li></ul>
Direct and develop HIT/IT for NBS LTFU	<ul style="list-style-type: none"><li>• Uniform data set</li><li>• Disease specific data set</li><li>• Transfer to NLM</li></ul>
Identify public health data set	<ul style="list-style-type: none"><li>• Uniform data set</li><li>• Disease specific data set</li><li>• Public health measures</li></ul>
Complete readiness assessment	<ul style="list-style-type: none"><li>• Meaningful use assessment and report</li></ul>





# National Projects-Laboratory

- ◆ **Laboratory Emergency Preparedness Exercises**
    - **Partnership with APHL and NCC**
    - **Scenario driven tabletop exercises conducted with state nbs and confirmatory laboratories through the RCs.**
    - **Uses elements of the CDC/HRSA conPLAN (Newborn Screening Saves Lives Act of 2007)**
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# Cross-Regional Projects- Education and Training

## ◆ Education Activities

- *Genetics and Your Health Brochures*
- RCs have partnered with Genetic Alliance to assist in dissemination of new materials and tools.

## ◆ Training Programs

- Genetic Metabolic Nutrition and Expanded NBS Course
  - Sickle Cell Peer Educators Training Program
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# Cross-Regional Projects- Follow-Up and Treatment

- ◆ **Inborn Errors of Metabolism Information System (IBEM-IS)**
  - ◆ **MyEIF**
  - ◆ **Data required for LTFU**
  - ◆ **LTFU information systems requirements**
  - ◆ **Access to Medical Foods Survey**
  - ◆ **Metabolic Care Plans/Guidelines**
  - ◆ **Quality Improvement**
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# Cross-Regional Projects- Laboratory

## ◆ MS/MS Data Project

- Started as a Region 4 project in 2004, this project continues to expand and currently includes states from all seven genetics regions as well as international participants from other countries; goal is to improve laboratory quality improvement by per comparison and clinical validation of MS/MS cutoff values.
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**Thank you**

