



Headlines and Highlights

from the

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

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The NCC is funded by U22MC03957, awarded as a cooperative agreement between the Maternal and Child Health Bureau/Health Resources and Services Administration, Genetic Services Branch, and the American College of Medical Genetics.



The National Coordinating Center (NCC) for the Regional Genetic and Newborn Screening Service Collaboratives (RC)

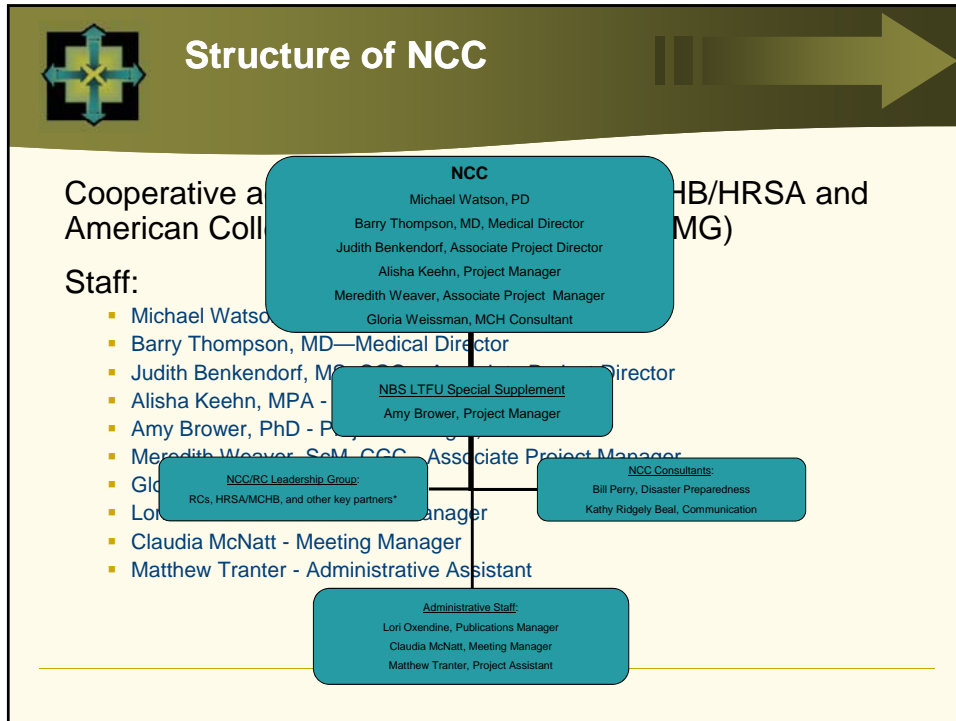
A quick review of who we are:

- NCC staff and project goals

Workgroups and Project Updates:

- Communication Activities
- Visiting Professorships
- Cultural Competence
- Medical Home Workgroup
- Transition Workgroup
- ACT Sheet Workgroup
- Telegenetics Workgroup

Collaborating for the future



Overarching Goals of the NCC

All NCC activities work toward:

- Facilitating the movement of quality genetic and NBS services to local communities;
- Building bridges between public health, primary care/medical home, geneticists/specialists, and patients/families.



Communication



Ongoing activities



- *NCC Collaborator* (quarterly newsletter)
- Bi-weekly NCC Notes (starting July 2011)
- Inter-RC communication via monthly conference calls with all PDs, NCC, and GSB/MCHB
- Triannual calls with each RC, HRSA, and the NCC



NCC Activity: AAP Visiting Professorships



AAP--using funds from NCC subcontract--has sponsored Genetics (GVP) and Medical Home Visiting Professorships (MHVP)

- MHVPs awarded to SERC and MSGRCC
- GVPs awarded to AAP Chapters in South Dakota, Virginia, and Washington D.C.
- The purpose of the GVP and MHVP is to provide an opportunity to enhance medical home education for providers and families within the Regional Collaboratives and to expand genetics/newborn screening related educational opportunities for primary care providers



Cultural Competence: Bringing Genetic Services to Special Communities

Special satellite session at 2011 ACMG Annual Meeting, “Screening for Carnitine-Palmitoyl Transferase, Type 1A (CPT1A) in First Nations Populations: A Community Conversation”

- ◆ Building upon the successful 2010 ACMG satellite session with the Navajo Nation and MSGRCC’s work with the Navajo Nation, NCC used the ACMG annual meeting setting, Vancouver, B.C., to bring together two unique approaches to screening for CPT1A—British Columbia and Alaska
- ◆ Partnered with ‘Kloshe Tillicum’ British Columbia (BC), Yukon Territories Network Environment for Aboriginal Health Research, and ACMGF
- ◆ Special Article in the most recent *NCC Collaborator*



Medical Home and Transition Workgroups

A central goal of the RCs has been to ensure that individuals 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.

These two workgroups will assist the local RC efforts by:

- Clarifying the definition of the medical home and transition;
- Identifying and sharing promising practices among the RCs;
- Engaging in activities that will facilitate improved communication and linkages between genetic expertise and primary care providers; and
- Moving regional projects to the national level as they develop.



ACT Sheet Workgroup

- ◆ New ACT Sheets focus on genetic tests, including carrier screening and tests commonly requested by primary care providers, transition to adult care, and family history
 - ◆ Began subgroup work around developmental disability algorithms and transition (July 2011 meeting); full workgroup to meet fall 2011.
 - ◆ AAP/NCC QuIN Project recently completed; conducted utility analysis of ACT Sheets.
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Telegenetics Workgroup

- ◆ Telegenetics workgroup restructured and met May 2011
 - ◆ Monthly calls established
 - ◆ Actively seeking partnering opportunities with other national organizations (HRSA OAT, now part of OHIT; ATA)
 - ◆ Submitting abstracts highlighting RC activities to national meetings
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Collaborating for the future



- ◆ HRSA's Genetic Services Branch strategic planning meeting October 2010
 - ◆ RCs and NCC held strategic planning session November 18, 2010 at the annual in-person meeting
 - Major ideas/suggestions:
 - Changing models of delivery of genetic services
 - Moving from a focus on NBS to focus on life course
 - Summary Themes:
 - When to [sustain](#) and when to [innovate](#)
 - When to [collaborate](#) and when to [compete](#)
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