



REMINDER!

May 2010

**Mountain States
Genetics Annual
Meeting**

July 13-15, 2010

Renaissance
Denver Hotel
3801 Quebec St.
Denver, CO 80207

[Click here for
meeting agenda](#)

Greetings!

The good news in April for Mountain States Genetics Regional Collaborative Center (MSGRCC) was funding of a supplement to us from the Health Resources and Services Administration (HRSA). This supplement of \$45,000 will fund 2-3 projects in our region that will increase access to genetic services through the use of distance strategies, including telemedicine. If this is an area of interest for you, visit http://msgrcc.org/RFA_2010.html to review the Request for Applications.

The MSGRCC Newborn Screening (NBS) Workgroup met on February 6, 2010 in Phoenix for their mid-year meeting. **Jeff Botkin** (Utah) and **Susan Tanksley** (Texas) co-chaired the meeting. To start the meeting, I provided the group with an update on the new recommendation from the Secretary's Advisory Committee on Hereditary Disorders in Newborns and Children (SACHDNC) to add Severe Combined Immunodeficiency (SCID) to the uniform newborn screening panel (<http://www.geneticalliance.org/pr.scid.achdnc>). The Secretary of Health and Human Services, **Kathleen Sebelius**, has endorsed the panel, including SCID, recommended by the SACHDNC. The Workgroup discussed the burden this could create on already stressed state budgets and health departments; states in our region will deliberate on whether to include SCID in their own newborn screening programs in the future.

The NBS Workgroup next heard updates from the states on their newborn screening activities. Colorado reported that the Colorado Department of Public Health and Environment (CDPHE) and the Inherited Metabolic Diseases Clinic at The Children's Hospital have been awarded a large grant from HRSA to develop health information technology solutions for improving newborn screening, diagnosis, and follow-up. Related to this project, a web-based integrated data system is now up and running for newborn hearing screening data management, and a similar system for newborn metabolic screening will be in place within the year. Also related, the Colorado Newborn

Screening Lab has added a PerkinElmer "web access" feature that will allow submitting laboratories and contracted subspecialists to view newborn screening results through the Internet. The lab will pilot the system with laboratories of the largest birthing centers and subspecialty centers in Colorado. As a component of the HRSA grant, these web solutions for information sharing will also include Wyoming. Arizona was recently awarded a data integration grant from the Centers for Disease Control and Prevention (CDC) that will focus primarily in newborn hearing screening. The state also received a supplement from HRSA to reduce loss to follow-up in the hearing program. New Mexico has a new information system for newborn screening case management. A new requirement for midwives has been instituted; midwives are now required to receive newborn screening training, and questions related to newborn screening are included on the New Mexico licensure exam. Utah is also a recipient of a large grant from HRSA for effective follow-up for newborn screening. This grant will allow newborn screening information to be added to the state's Clinical Health Information Exchange (CHIE). Utah has been screening for Cystic Fibrosis (CF) for one year, and they have identified a larger number of infants than predicted. These infants have also been sicker than expected. Utah, Texas and Colorado conducted a roundtable at the May Newborn Screening Symposium of the Association of Public Health Laboratories (APHL) to share strategies on CF screening.

Montana expanded screening in January, 2008 to include the 29 tests included on the uniform panel. The state has made good progress since then in developing service contracts with subspecialists to serve these babies and families. Montana hosted its first "Metabolic Day" for patients, family members and providers in August, 2009, and this event will be repeated on August 14, 2010. Texas has introduced a new long term follow-up (LTFU) database, and hospitals can now submit demographic data via HL7 transfer, which allows different health care systems to talk to each other. About 5-6% of demographic information on newborns is now submitted on-line in Texas. As a component of the settlement of a lawsuit on stored dried blood spots, Texas will destroy all previously stored spots, and in the future parents will be able to opt out of storage.

The Workgroup heard a presentation on short-term follow-up from **Brad Therrell**, Director of the National Newborn Screening and Genetics Resource Center (NNSGRC). The LTFU committee of the Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) recommended to SACHDNC that the newborn screening serial number should be included as a required field on the standard national birth certificate, and this issue will be discussed further at SACHDNC. Brad also provided an overview of the National Newborn Screening Information System (NNSIS), a database compiled by NNSGRC that includes information on newborn screening testing and short term follow-up from all of the states. You can access information from NNSIS through the NNSGRC website (<http://nnsis.uthscsa.edu>).

The Newborn Screening Workgroup is working on the following activities in preparation for the MSGRCC Annual Meeting (July 13-15 in Denver): organization of a data sharing group to share data on new technologies, second screens and other issues of interest to states in the region; creation of better linkage between the NBS Workgroup and

the Genetic Alliance; and exploration of expansion of the Texas Newborn Screening Performance Measures Project to other states in the region. We hope to see all of you at the Annual Meeting to hear updates from this active workgroup and from all of our other workgroups and projects. Visit http://www.msgrcc.org/2010_Annual_Meeting.html for more information on the Annual Meeting. We're looking forward to seeing you face to face to identify our common priorities for the coming year, and to catch up on your news!

As always, if you have questions or comments related to any MSGRCC activities, please feel free to contact me, Joyce Hooker or Liza Creel. Staff contact information:

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Warm regards,



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