



REMINDER!

April 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!

March was a busy month for the MSGRCC staff, as we prepared our non-competitive renewal application to HRSA for year 4 of our 5 year grant. We were especially proud of the progress reports we could submit on behalf of our workgroups (Newborn Screening, Telemedicine, Emergency Preparedness, and Consumer Advocacy) and the projects funded by MSGRCC (Metabolic Newborn Screening Long-term Follow-up Study, Hemoglobinopathies Newborn Screening Follow-Up, Native American Education in Genetics, Improving Medical Homes and Transition Outcomes for Youth Served in IMD Clinics, Laboratory Quality Assurance, and Emergency Preparedness Planning). As you know, I'm planning to report on each workgroup over the next few messages, and I'll also provide you with information on our funded projects.

The Emergency Preparedness Workgroup met on February 5, 2010 for their mid-year meeting in Phoenix. **Donna Williams** (Texas) and **Lynette Borgfeld** (Texas) co-chaired the meeting. Workgroup members provided updates on current emergency preparedness activities in their states, as well as any needs that have been identified. Of particular interest, **Ward Jacox** reported that Arizona has a new Memorandum of Understanding (MOU) with four states in the region (Utah, Arizona, New Mexico and Colorado) to provide emergency preparedness back-up for newborn screening. The logistics of how the MOU will actually work are to be determined. Ward will share details with the workgroup as they become available. Lynette Borgfeld updated the workgroup on planning activities for emergency preparedness at the Texas Department of State Health Services. Of note, the Newborn Screening Program is authorized to provide mutual aid to other states, and staff is currently working with Florida to develop a mutual aid agreement. Texas has developed a list of 10 questions for development of the agreement, and Lynette agreed to share this list with the workgroup. **Linda Beischel** (Montana) reported that Montana has had an MOU with Wisconsin for laboratory back-up since 2005, and Linda will provide the workgroup with a copy of the MOU.

Liza Creel, MSGRCC Project Coordinator, presented the results of a recent MSGRCC survey on laboratory capacity and emergency preparedness in state newborn screening laboratories in the region. After discussion, it was agreed that the survey should be refined, additional questions should be added, and the survey will be sent back to states for further information. Liza, **Joyce Hooker** (MSGRCC Project Manager), Donna and Lynette reviewed emergency preparedness tools available from other regions and organizations, including the MSGRCC Clinical Preparedness Planning Tool developed by **Dr. Johan Van Hove** and his colleagues at the University of Colorado School of Medicine.

As a result of the meeting, the Emergency Preparedness Workgroup agreed on their regional charge: to contribute expertise in the development of regional/interregional emergency backup systems for newborn screening and genetic services that will assist laboratory, follow-up and clinical services in the Mountain States region to be prepared for both catastrophic and management emergencies. In preparation for their meeting in July, the workgroup will share all state MOUs, gather information on legal barriers regarding MOUs, include state emergency preparedness data on the MSGRCC website, and recruit clinicians to participate on the workgroup.

On April 6, 2010, Lynette Borgfeld, co-chair of the MSGRCC Emergency Preparedness Workgroup, represented our region at the National Coordinating Center's Emergency Preparedness Workgroup meeting in Bethesda, MD. This meeting focused on regional and national preparedness activities. We will update you on these and other emergency preparedness activities during the July Annual Meeting.

APHL will hold the 2010 Newborn Screening and Genetic Testing Symposium in Orlando, Florida May 3-6; this meeting will include a post-conference session on newborn screening data collection and the National Newborn Screening Information System. Various committees of the Newborn Screening Translational Research Network (NBSTRN) will be meeting in late April and May. NBSTRN is funded by NIH to identify best practices in treatment of disorders identified by newborn screening and translate them into practice. The Secretary's Advisory Committee on Hereditary Disorders in Newborns and Children (SACHDNC) will be meeting May 13-14 in Washington, DC, and we expect additional discussion of disorders nominated for the uniform newborn screening panel, including cyanotic congenital heart disease and Hemoglobin H. I will be attending the meeting along with Joyce Hooker, who represents the regional collaboratives on the SACHDNC Education and Training Subcommittee. The SACHDNC meeting will be offered via web cast for those who cannot attend in person. Information on how to access the web cast will be available one week prior to the meeting at <http://events.SignUp4.com/ACHDNC0510>. For more information on SACHDNC, visit their website: <http://www.hrsa.gov/heritabledisordrescommittee/>. Since the deliberations and recommendations of all of these groups have impact on what we do here in the Mountain States, we'll provide you with

updates following each of these meetings.

Meanwhile, please keep the dates for our MSGRCC annual meeting (July 13-15 in Denver) on your calendar. We hope to see you there! Click here for more information on the annual meeting and to see the draft [agenda](#).

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:

Celia Kaye, Project Director, MSGRCC -
Celia.Kaye@ucdenver.edu

Joyce Hooker, Project Manager, MSGRCC -
jhooker@msggcc.org & 303-978-0125

Liza Creel, Project Coordinator, MSGRCC -
lcreel@msggcc.org & 512-279-3906

Website: www.MountainStatesGenetics.org
Also, don't forget to complete our regional communications survey:
<http://www.surveymonkey.com/s/mountainstatescommunication>

Warm regards,



Celia I. Kaye, M.D., Ph.D.

Project Director, MSGRCC

[Forward email](#)

Texas Health Institute | 8501 North MoPac Expressway | Suite 300 | Austin | TX | 78759