



February 2010

### Greetings!

Two important meetings have taken place since [my last message](#). The Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) met in Washington, DC, January 21-22, 2010. The Committee reviewed the evidence for recommending the addition of Severe Combined Immunodeficiency Disorder (SCID) to the newborn screening panel. After careful consideration, including testimony from parents of affected children, the Committee voted to recommend to the Secretary of Health and Human Services, Kathleen Sebelius, that SCID be added to the panel. Once the written report is submitted to the Secretary she will have 180 days to respond to SACHDNC. For more information on SACHDNC, please visit their website: <http://www.hrsa.gov/heritabledisorderscommittee/>.

The second "meeting" was actually a remarkable series of working sessions in Phoenix, February 4-7, of the MSGRCC Advisory Council, our four workgroups (Telemedicine, Emergency Preparedness, Newborn Screening, and Consumer Advocacy), and participants of the laboratory quality assurance projects led by Dr. Marzia Pasquali. While most members were able to travel to Phoenix for these sessions, many additional members were able to participate using teleconference, webinar, and Skype. Much new information was available to the groups: reports on newborn screening in each state, data from a new emergency preparedness survey, practical information on promoting distance strategies, and performance data from our National Coordinating Center. The Consumer Advocacy workgroup finalized its white paper on recruitment of diverse membership, emphasizing the Navajo Nation (The People). It was completely energizing to see friends and colleagues from throughout the region. This energy was translated into specific plans for each workgroup for the next six months, leading up to the MSGRCC annual meeting in Denver July 13-15, 2010. Please be sure this meeting is on your calendar!

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**, PI, MSGRCC - [Celia.Kaye@ucdenver.edu](mailto:Celia.Kaye@ucdenver.edu)

**Joyce Hooker**, Project Manager, MSGRCC

[jhooker@msggcc.org](mailto:jhooker@msggcc.org) & 303-978-0125

**Liza Creel**, Project Coordinator, MSGRCC

[lcreel@msggcc.org](mailto:lcreel@msggcc.org) & 512-279-3906

Website: [www.MountainStatesGenetics.org](http://www.MountainStatesGenetics.org)

Also, don't forget to complete our regional communications survey:

<http://www.surveymonkey.com/s/mountainstatescommunication> .

I wish you good health and good fortune in 2010, and I'm looking forward to seeing you at our upcoming events.

Warm regards,



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

Principal Investigator, MSGRCC

Previous PI Messages:

[January 2010](#)

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