



REMINDER!

June 2010

### Mountain States Genetics Annual Meeting

July 13-15, 2010

Renaissance  
Denver Hotel  
3801 Quebec St.  
Denver, CO 80207

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meeting agenda](#)

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#### Greetings!

MSGRCC received more good news in May, when we were notified by the Genetic Services Branch, Maternal and Child Health Bureau, HRSA that our continuation grant for fiscal year 2010-2011 was fully funded. This will allow us to continue the support of projects, workgroups, and other activities in our Mountain States Region.

This month, MSGRCC is completing final arrangements for our annual meeting in Denver, July 13-15, 2010. **Dr. Ned Calonge**, Chief Medical Officer, Colorado Department of Public Health and Environment and member, Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC), will be our keynote speaker, highlighting the evolving role of public health and newborn screening programs during a time with increasing demands and fewer resources. **Dr. Calonge** will also discuss the role of public health agencies in assuring access to genetic services for infants identified through newborn screening and all individuals with genetic disorders. The schedule for the meeting also includes a presentation from **Dr. Ricky Bass** on health literacy, an introduction to telemedicine from **Dr. Dale Alverson**, reports on regional projects, workgroup meetings, comments from leaders of federal agencies and national offices, a panel of young adults who will discuss transition from pediatric to adult services, and plenty of time for networking. Visit [http://www.msgrcc.org/2010\\_Annual\\_Meeting.html](http://www.msgrcc.org/2010_Annual_Meeting.html) for more information on the annual meeting.

The MSGRCC Consumer Advocacy Workgroup met on February 7, 2010 in Phoenix for their midyear meeting. This active group, chaired by **Joe Martinec** (Texas) and **Rod Slaght** (CO), completed work on their white paper describing issues and recommendations related to the recruitment of minority individuals, particularly Native Americans, to participate in regional collaboratives and other groups whose missions relate to genetic services and genetic advocacy. The white paper, entitled *The Life Rope: Engagement of Diverse Populations for Recruitment and Representation in Genetics*, will be submitted to a

peer reviewed journal for publication. Since the February meeting, some of the major points of the white paper were presented to the SACHDNC Subcommittee on Education and Training by **Joyce Hooker**, to the other Regional Collaborative Centers by **Liza Creel**, and abstracts have been submitted to the Society of Public Health Educators and the Academy for Health Equity for possible presentations at their 2010 meetings. We are very grateful for the thoughtful and sustained efforts of this workgroup on this project. We believe it will impact the abilities of MSGRCC and other regional collaboratives to enhance participation of consumers of Native American background in their activities.

The Consumer Advocacy Workgroup has been successful in appointing members of the workgroup to serve on all of the other MSGRCC workgroups (telemedicine, emergency preparedness and newborn screening). This participation has emphasized again the importance of including the perspectives of patients and family members as we evaluate the genetic services available in our region, strive to increase access, plan for new projects, and set priorities for the future. The Consumer Advocacy Workgroup has committed to appointing a member to participate in the oversight process of each of the projects funded by MSGRCC, and it is a goal of the coming fiscal year to engage these consumer members actively in the conference calls that review the activities of these projects.

For those of you who will attend the Annual Meeting in July, please make a point of saying hello to me and the other MSGRCC staff. We want to share your concerns and successes! For those who can't be at the Annual Meeting - we wish you a wonderful summer, with at least a little time for fun and relaxation.

Warm regards,



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