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July 2010

Greetings !

MSGRCC held our annual meeting in Denver, Colorado July 13-15, 2010. The meeting was attended by nearly 70 providers, public health specialists, individuals with congenital conditions and their family members, partners from national organizations, and other stakeholders. Attendees participated in a wide variety of workshops, presentations and panels on regional and national projects and activities. There was also time (never enough!) for good food, good conversation and networking.

This short message can't begin to capture the scope of everything that was accomplished at the meeting, so I'll select just a few highlights, with more detailed information to follow in future messages. **Ned Calonge**, Chief Medical Officer of the Colorado Department of Public Health and Environment, gave the keynote address, focusing on promises, practices, processes and policies surrounding genetic testing and genetic medicine. We hope to provide you with a summary of Ned's provocative presentation later in the summer.

Sara Copeland, Deputy Branch Chief, Genetic Services Branch (GSB), Maternal and Child Health Bureau, HRSA, summarized the current activities of GSB nationally and provided an overview of activities GSB hopes to launch in the near future. New activities include programs to enhance information available to providers and families (the Newborn Screening Clearinghouse), a program to develop a family history tool for prenatal providers, and a new program to promote early and continuous screening through the medical home. Future planned activities will address the maldistribution of all aspects of genetic services by focusing on emergency preparedness, education of providers and consumers, and utilization of telegenetics/telehealth.

A panel on the addition of Severe Combined Immunodeficiency Disease (SCID) to the recommended panel of newborn screening disorders was presented by **Chris Kus**, Associate Medical Director of the Division of Family Health, New York Department of Health, and

representative to the Secretary's Advisory Committee on Hereditary Disorders in Newborns and Children (SACHDNC); **Vickie Thompson**, Colorado Audiology Consultant and Director of Newborn Screening Programs at the Colorado Department of Public Health and Environment; and myself. We covered the process of adding a new disorder to the recommended panel through SACHDNC, clinical and treatment issues, and the process of introducing a "new" disorder to a state newborn screening panel.

The highlight of the annual meeting was the presentation of a panel on transitioning from pediatric to adult health services by **Gillian Aitken**, **Linden Aitken**, and **Annaliese Martinec**, three young women who are affected with metabolic disorders. Coming at the end of a long and full day, these young women captured the attention and the hearts of everyone at the conference with their honest, articulate and thought-provoking stories. We lost track of time, listened, and shared ideas with these remarkable young women. Their stories need to be shared with policy makers in our states, nationally, and within insurance companies whose decisions impact the choices that are available to young persons as they prepare to assume their adult roles and responsibilities.

Added to all of this were workgroup meetings and updates on projects funded by MSGRCC and other projects of interest in the region. You can review the minutes of the workgroup meetings on the MSGRCC website (www.MountainStatesGenetics.org). The Advisory Council also met to review proposals submitted in response to our call for innovative projects in telemedicine and telehealth. We will provide you with more information on the approved projects as they are launched.

It was a wonderful meeting, and many thanks are due to the workgroup and project leaders, who prepared for the meeting so effectively, and to the MSGRCC members who attended and participated so fully. I enjoyed catching up with so many of you! Now, I hope you find a little time for vacations and relaxation as the summer concludes (snow comes early here in Colorado!)

Warm regards,



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