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October 2010

Greetings:

Representatives from MSGRCC attended the September meeting of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) in Washington, DC. Activities of SACHDNC impact newborn screening activities in each state, as we learned when Severe Combined Immunodeficiency Disorder (SCID) was added to the recommended panel for newborn screening a few months ago. This meeting was equally important for states, as they consider what additional disorders should be added to the newborn screening panel.

At this meeting, SACHDNC discussed the evidence for adding critical congenital cyanotic heart disease (CCCHD) to the recommended panel. Screening for this set of disorders would occur by pulse oximetry of all newborns prior to discharge from the newborn nursery. After a lively discussion and testimony from neonatologists, cardiologists and families, the following recommendation was approved by the committee: "Although there are recognizable evidence gaps, there are compelling reasons for recommending screening newborns for critical congenital cyanotic heart disease (CCCHD)." SACHDNC recommended the addition of screening for CCCHD with the understanding that certain highly important activities would take place in a timely manner:

- The National Institutes of Health shall fund research activities to determine the relationships among the screening technology, diagnostic processes, care provided, and the health outcomes of affected newborns with CCCHD as a result of prospective newborn screening;
- The Centers for Disease Control and Prevention shall fund surveillance activities to monitor disease link to infant mortality and other health outcomes;
- The Health Resources and Services Administration shall guide the development of screening standards and infrastructure

needed for the implementation of a public health approach to point of service screening for CCCHD;

- The Health Resources and Services Administration shall fund the development of, in collaboration with public health and health care professional organizations and families, appropriate education and training materials for families and public health and health care professionals relevant to the screening and treatment of CCCHD.

This recommendation will now go to the Secretary of the Department of Health and Human Services for review and ultimate action. If she endorses the recommendation, CCCHD will be added to the recommended uniform panel for newborn screening. As you know, action is taken to add any disorder to a state's newborn screening panel at the level of a state's newborn screening advisory committee and/or legislature. We will be keeping track of how states in the Mountain States region respond to the SCID recommendation and to this recommendation, if it is approved by the Secretary. If you feel that a forum for discussing these issues would be helpful to you, please let me know so that we can organize this.

MSGRCC is working on arrangements for our mid-year meeting in February or March, 2011. We received funding from the American Academy of Pediatrics to plan another Medical Home Visiting Professorship, and we hope to hold the visiting professorship in conjunction with the mid-year meeting. More information on this meeting will be forthcoming as we complete the planning.

Liza Creel presented the work of the Consumer Advocacy Work Group on recruitment of minority population representatives into activities of the regional collaboratives at the meeting of the Academy for Health Equity in Denver, Colorado on August 19th; **Joyce Hooker** will present information on MSGRCC, the Mountain States Metabolic Consortium's uniform dataset for long-term follow-up of metabolic disorders identified through newborn screening, and Murray Brilliant's project on community conversations with Native American populations at the American Public Health Association's Annual Meeting in Denver, Colorado on November 10th. These opportunities to showcase our activities resulted directly from the outstanding work of our MSGRCC workgroups and projects. Thanks to all those who made this excellent work possible!

Halloween is just around the corner, and I hope all of you have your costumes chosen and your toothbrushes available for use after the big night. I'll be looking for you on my doorstep when the goblins prow!

Warm regards,



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