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January 2011

Greetings:

2011 is off to a quick start for MSGRCC, genetics providers, and families in our region. This month a major work group, funded as part of an NIH study on the use of residual dried blood spots for research, met in Salt Lake City. Hosted by **Jeff Botkin** and his research team at the University of Utah, the workgroup included individuals from the Mountain States, other regions, and national entities including the March of Dimes, CDC, HRSA, NNSGRC, and parent support organizations. Individuals with expertise in the law, public policy, bioethics, public health and clinical medicine attended. Parents of individuals with conditions identified by newborn screening were also at the workgroup meeting. Following an in depth review of issues related to the use of dried blood spots for research, as well as data collected from the public by the research team using a variety of methods, there was lively discussion of the ethical issues that should inform public policy in this area. Jeff and his group will be reporting on their findings through meetings and publications in the future.

Later this week, the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) will convene to discuss the evidence report on newborn screening for hyperbilirubinemia, and the status of state implementation of newborn screening for Severe Combined Immunodeficiency Disorder (SCID). There will be further discussion of the possibility of newborn screening for critical cyanotic congenital heart disease (CCCHD) using pulse oximetry, as well as results of a national survey of recent and prospective mothers about newborn screening. Stay tuned for more information next month.

Closer to home, the two projects funded last fall through our supplemental funds from the Genetic Services Branch are up and running. Through these projects, *the Montana Tele-genetics Project: Improving Access, Educating Providers and Consumers* and *the Genetic Counseling for Early Hearing Detection and Intervention (EHDI) using Distance Strategies*, and our engagement of telemedicine

stakeholders in the Mountain States Region, we've seen increased interest in telemedicine from genetics providers in the region. A major focus of MSGRCC is access to care, and these activities, utilizing telemedicine as a distance strategy, represents fulfillment of a goal of MSGRCC to become actively engaged in improving access to services, within our obvious resource constraints.

MSGRCC has asked for progress reports from the directors of our regional projects, in preparation for submission of our non-competitive renewal in March (year 5 of 5 for our cooperative agreement will begin in June, 2011). We hope to share these reports with you in subsequent monthly messages. MSGRCC providers are identifying issues and developing guidelines that will influence policies and service models nationwide. We're proud to be a part of these important projects.

Finally, MSGRCC is preparing for the mid-year, face to face meetings of our workgroups (Newborn Screening, Emergency Preparedness, Consumer Advocacy, and Telemedicine) in conjunction with our second Medical Home Visiting Professorship (MHVP) workshop, funded through a joint public/private partnership between the Maternal and Child Health Bureau/Health Resources and Services Administration, the National Coordinating Center for the Regional Genetics and Newborn Screening Service Collaboratives, housed at the American College of Medical Genetics, and the American Academy of Pediatrics. As Visiting Professor, **Chuck Norlin**, MD, Development Director of The Medical Home Portal, will describe the Portal and lead a discussion with providers, consumers, and resource organizations such as state 2-1-1 providers to identify ways by which this system can enhance medical home services to individuals with genetic conditions. The mid-year workgroup meetings and the MHVP will take place in Tempe, Arizona on February 24-27. Please look for your invitations to these meetings and let us know if you will be able to attend. You can also access additional information about these meetings at the following links: http://msgrcc.org/2011_Mid-year_Meeting.html and http://msgrcc.org/2011_MHVP_Meeting.html.

I'm looking forward to seeing many of you in just a few weeks. Meanwhile, stay warm, enjoy your work and play, and take pleasure in reflecting on all the good you do for the children and families in our region.

Warm regards,



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