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November/December 2010

Greetings!

Snow has come to the Mountain States, and in the cool months, I always feel energized to finish the tasks that have been populating my "to do" list. The list includes planning for the future of MSGRCC, as we work our way through year 4 of our 5 year grant cycle. In November, the project directors and project managers of the seven genetics and newborn screening regional collaborative centers (the RCs) and the National Coordinating Center (NCC) met in Gaithersburg, Maryland. The purposes of the meeting were to review current activities and to continue HRSA's Genetic Services Branch (GSB) strategic planning process.

The RCs and NCC have worked hard to make progress in long term follow-up, emergency preparedness, transitioning young adults from pediatric health care to adult services, development of distance strategies such as telemedicine, and enhancing medical home services. MSGRCC has provided leadership in most of these areas and has been active in all of them; looking forward, it is likely that GSB will continue to work on these activities. However, because progress has been made on all of these areas in all of the regions, it is likely that new areas of focus will also be identified. Most important, I think, is the emerging emphasis on the life course as a theme for genetic services. While continuing to acknowledge the importance of newborn screening, GSB is likely to devote some resources to genetic services related to prenatal care, reproductive health, and adult screening. There will also be recognition that prevention of morbidity and mortality from genetic disorders is not solely in the hands of the medical care system; engaging families and community resources in screening, prevention, and provision of care will receive significant attention. Specific priorities related to this broad focus are likely to include integration of genetics with primary care in the medical home model, family centeredness, and health information exchange as part of the system infrastructure. Over the next year, the RCs and NCC will work with GSB to refine these priorities and identify ways to work on them in an environment of limited funding. MSGRCC will need the ideas of all of our members to provide

input that recognizes the unique demographics and geography of our region.

How can you provide us with input as this planning proceeds? Many of you are actively involved in MSGRCC workgroups or the Advisory Council, and we will be reporting to these groups on the planning process and the emerging priorities as we learn more about them. MSGRCC workgroups will be meeting in Phoenix Feb 25-27, 2011, and this will provide us with the opportunity to talk to you and hear what you think about future directions. The MSGRCC Annual Meeting will again be held in the summer of 2011, and we will set aside time on the agenda to report to you and hear your ideas about these priorities. As we plan for this meeting, we'd like to know how continuing education credits might impact your likelihood of attending. Please take a moment to respond to this short survey and give us your feedback - <http://www.surveymonkey.com/s/KT6SX65>.

Another opportunity will be the second MSGRCC Medical Home Visiting Professorship, supported by the American Academy of Pediatrics and the National Coordinating Center, to be held on February 24, 2011 in conjunction with the mid-year workgroup meetings in Phoenix. **Dr. Chuck Norlin**, Director of the Medical Home Portal Project, Professor of Pediatrics and Division Chief of General Pediatrics in the Department of Pediatrics at the University of Utah Health Sciences Center, will discuss the medical home portal as a tool to enhance community participation in provision of services to children with genetic disorders and other special health care needs. Given the emerging priority for community involvement and family centeredness for genetic services across the lifespan, Dr. Norlin's presentation should provide us with an opportunity to focus on these areas in our region in advance of what we hope will be additional funding for these kinds of activities. We hope you can join us at some or all of these meetings to talk about the future and plan for what we will be doing in our region in the next few years.

Meanwhile, the winter holidays are upon us, and we at MSGRCC wish you good times with family and friends, safe travels, and at least a few minutes for reflection on the good work of the past year and the wonderful opportunities before us. In the spirit of creating time for family and friends, there will be no MSGRCC Message from the PD in December. May all your December moments be cozy!

Warm regards,



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