



## Message from the Project Director Celia I. Kaye, MD, PhD

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October, 2011

### Greetings!

Halloween in Colorado followed a big snowstorm that clogged streets with slush and began to fill the ski areas with the snow that is so beloved by people here. I wonder if winter is beginning to make itself felt where you are.

Speaking of winter -- save the date! We've scheduled our mid-year workgroup meetings for February 24-26, 2011 in Phoenix, Arizona. The workgroup schedule is being finalized, and you will receive an official invitation from us by the end of November. If you traveled to San Diego this week for the APHL Newborn Screening and Genetic Testing Symposium, I hope you stopped by our poster on the Laboratory Capacity Survey that the MSGRCC Emergency Preparedness Workgroup conducted last year. Joyce Hooker and Liza Creel attended the meeting and I know they enjoyed visiting with many of you!

As we prepare for the mid-year meetings, we'd like to share some recent workgroup activities with you. All workgroups met in July during the MSGRCC Annual Meeting.

### Consumer Advocacy Workgroup

The Consumer Advocacy Workgroup met prior to the start of the larger MSGRCC Annual Meeting. Co-chairs Joe Martinec and Rod Slaght led another fabulous meeting of this dedicated group of parents, families, and patients. Those members that attended regional or national meetings during the previous six months gave summaries of their experiences. Workgroup members had attended both the American College of Medical Genetics Annual Meeting and the Genetic Alliance Annual Conference. Members also shared updates on their personal and

professional activities since the last in-person meeting. They continued discussion of how state budget cuts may impact children and families and some of the national efforts underway to minimize disruption to routine care for children with heritable disorders and other special health care needs. The participants spent a considerable amount of time at the meeting beta testing the new MSGRCC website and helping staff identify areas for improvement.

### Newborn Screening Workgroup

The Newborn Screening Workgroup, chaired by Jeff Botkin and Susan Tanksley, had over 50 people in attendance in person or by phone! Workgroup members shared updates from their states on the status of SCID screening, new issues impacting their newborn screening programs, and the status of health information technology implementation. States are at different stages of both SCID implementation and expansion of health information technology, and many states are still encountering budget issues within the newborn screening program and health department. At the meeting, the workgroup heard presentations on MSGRCC-funded projects, including the Metabolic Newborn Screening Long-term Follow-up Study, the Hemoglobinopathies Newborn Screening and Follow-Up Project, and the Laboratory Quality Assurance Projects. Workgroup members also discussed a number of follow-items from previous meetings. They identified two areas - provider education and public health professional education - where the workgroup can help identify educational opportunities for members. Instead of organizing education sessions, volunteer workgroup members will help MSGRCC staff find educational opportunities offered by other organizations. If gaps in educational needs are identified, the workgroup can explore developing an educational session on its own. If you are interesting in volunteering to help find educational opportunities, please contact Liza Creel at [lcreel@msgbcc.org](mailto:lcreel@msgbcc.org). The workgroup is continuing to develop a laboratory subgroup that will focus specifically on issues in the state newborn screening laboratories in the region. The group expressed some interest in forming a follow-up or hearing subgroup to focus exclusively on those topics; these activities are pending.

An ongoing topic of discussion for the Newborn Screening Workgroup has been implementation of screening protocols for NICU babies. In November, 2009 the Clinical and Laboratory Standards Institute (CLSI) issued the Newborn Screening for Preterm, Low Birth Weight, and Sick Newborns; Approved Guideline to improve detection

of newborns at risk for disorders screened by state newborn screening programs. Some states have implemented screening protocols similar to the CLSI guideline, others have developed their own protocols, and some have not defined a standard protocol. At the July meeting, members of the MSGRCC Newborn Screening Workgroup expressed great interest in learning more about the CLSI guidelines and how other states have implemented similar or modified protocols. In response, MSGRCC organized a conference call focused on setting newborn screening guidelines for NICU babies. The call was held on August 29, 2011 and featured two speakers, Judith Tuerck, RN, MS and Julie Leudtke, BS, both of whom co-chaired the CLSI subcommittee that developed the guideline. The call agenda placed emphasis on discussion about how states in the Mountain States Region would proceed with setting their own guidelines. We look forward to hearing about these activities during our mid-year meeting!

#### Emergency Preparedness Workgroup

The Emergency Preparedness Workgroup, led by co-chairs Lynette Borgfeld and Donna Williams, also met in July. Each participant provided an update on emergency preparedness (EP) activities in his or her state, including any planning activities or exercises. Bill Perry, the National Coordinating Center's EP Consultant, summarized three recent tabletop exercises that took place in the Mountain States Region. The first was an exercise between Florida and Texas to test procedures for backup testing and case management if either state were to experience a catastrophic disaster. The second was the MSGRCC Regional EP Tabletop Exercise, where six states participated, some virtually, in an exercise designed to help states identify potential "bottleneck" areas that will be impacted if a large-scale emergency (pandemic flu in this exercise) were to occur. One of the early assumptions was that decreased staffing would greatly impact the ability of newborn screening programs to accomplish their objectives during an emergency; however, the exercise demonstrated that staffing wasn't as much of an issue as the failure of technological infrastructure (e.g. loss of a server). The third exercise was held during the July meetings with the Metabolic Consortium and focused on the clinical perspective of emergency planning. One need identified in this exercise related to not having a single database of all the service providers in the region to which providers and families can refer during an emergency. Bill also talked with the workgroup members about other EP-related activities that they could undertake.

## Telemedicine Workgroup

The Telemedicine Workgroup, chaired by Thelma McClosky-Armstrong and Brad Thompson, had an equally rich meeting in July. They heard presentations from both of the MSGRCC-funded telemedicine projects: the Genetic Counseling for Early Hearing and Intervention Telemedicine Project and the Montana Tele-genetics Project: Improving Access, Educating Providers and Consumers. In addition, the workgroup welcomed Mark Carroll, MD who is the Telehealth Program Director for the Indian Health Service (IHS). Dr. Carroll presented on the existing telemedicine infrastructure within IHS and his perspectives on expanding genetic services for children with heritable disorders. Dr. Carroll agreed to continue looking for partnership opportunities between IHS, MSGRCC, and the communities of Native American populations served in this region. Finally, the workgroup continued discussion of how telemedicine can play a role in supporting and strengthening the medical home, and gave MSGRCC staff the approval to proceed with drafting a white paper describing the conceptual model developed by the workgroup.

Sharing the outstanding work of our workgroups and projects was energizing last summer, and fall has seen the continuation of many productive activities. We'll tell you more about these other activities next month. Meanwhile, stay warm and take some time for reflection and fun.

Warm regards,



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