



September, 2011

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#### Greetings!

Although the frost is not yet on the pumpkins, the pumpkins themselves are ripening in Mountain States gardens. Soon we'll be able to use them in Halloween decorations and wonderful recipes for pumpkin bread and pumpkin pie. Where did the summer go?

#### SACHDNC Meeting

MSGRCC staff said good-bye to summer at the September 22-23 meeting of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) in Washington, DC. This was an action filled meeting, beginning with an announcement by out-going chair Rod Howell that Health and Human Services Secretary Kathleen Sebelius adopted the recommendation of SACHDNC that Critical Congenital Heart Disease (CCHD) be included on the recommended uniform panel for newborn screening. The recommendation from SACHDNC received additional review by the Interagency Coordinating Committee on Screening in Newborns and Children before being accepted by Secretary Sebelius. Point of care screening for CCHD is accomplished through pulse oximetry screening during the newborn period. Our states will now consider this recommendation and determine when and how to implement it on a state by state basis.

Much of the SACHDNC meeting this time was devoted to reflections on the progress of newborn screening since the committee was chartered in 2003. These included adoption of the original uniform panel of 29 core disorders for newborn screening by all states and territories, improvement in follow-up for hearing loss from 52% to 69%, development of the evidence review process for newborn screening disorders, and review of numerous work products of SACHDNC. Sharon Terry from the Genetic Alliance updated the group on the launch of Baby's First Test ([http://r20.rs6.net/tn.jsp?llr=ofyp6xbab&et=1107905631693&s=7901&e=001jxE0h5Q5VBer8XOZWrhjN6hSwfYLWibQ6b\\_SaSrCWtakTYmkS0W3vATZ83msx76wkdTkWk0i\\_Yjq4lGI08xvZjX7FH1IIE\\_AOM6Luw5uZE1N1y69yI18JA==](http://r20.rs6.net/tn.jsp?llr=ofyp6xbab&et=1107905631693&s=7901&e=001jxE0h5Q5VBer8XOZWrhjN6hSwfYLWibQ6b_SaSrCWtakTYmkS0W3vATZ83msx76wkdTkWk0i_Yjq4lGI08xvZjX7FH1IIE_AOM6Luw5uZE1N1y69yI18JA==)), the new website for the Newborn Screening Clearinghouse, and Mike Watson provided a progress report for the Newborn Screening Translational Research Network (NBSTRN), which is proceeding with the development of a virtual repository of dried blood spots and supporting states as they pilot additional disorders for newborn screening. Barry Thompson updated the group on the activities of the Regional Collaboratives and the National Coordinating Center, including development of the ACT sheets and follow-up measures for disorders identified by newborn screening, as well as reports on medical home, telemedicine and transition projects. As you know, MSGRCC is very active in all of these areas. Finally, each subcommittee (laboratory standards and procedures; education and training; follow-up and treatment) reviewed its charge and activities over the past several years and suggested new activities for the coming years. After recognizing Rod Howell for his remarkable service to all of us and to all children, Joseph Bocchini, M.D. was welcomed as the incoming SACHDNC chair. You can learn more about Dr. Bocchini and other new members of the SACHDNC [here](#).

#### Genetic Alliance 25th Anniversary Celebration

While in Washington, DC, we also had the pleasure of attending the Genetic Alliance 25th Anniversary Celebration at the National Geographic Society. The event honored innovators from the genetics, health and advocacy community, and our own Joyce Hooker was included as an honoree. To see the exhibit honoring Joyce, please visit this [link](#).



#### Newborn Screening Workforce Survey

The New England Genetics Collaborative (NEGC), the University of New Hampshire Survey Center, and the National Coordinating Center for the Regional Genetic and Newborn Screening Service Collaboratives (NCC) have just launched a national survey examining the newborn screening workforce. The MSGRCC has partnered with them to distribute the survey in our region and we hope you'll take a few minutes to complete it here: [http://r20.rs6.net/tn.jsp?llr=ofyp6xbab&et=1107905631693&s=7901&e=001jxE0h5Q5VBc1qNZ\\_GqAiIa4z1jcvkhOM7dpYw\\_VNFur7odnw50fmb-JyHVpDv5ermkVpS1X\\_hK7qv1MnZHYM1Hlo6zi7EAeSds2oBevMaSj0F80irBSF9DdMR6CDt7teL2aumIZy\\_wb2eFD0uLxDMQ==](http://r20.rs6.net/tn.jsp?llr=ofyp6xbab&et=1107905631693&s=7901&e=001jxE0h5Q5VBc1qNZ_GqAiIa4z1jcvkhOM7dpYw_VNFur7odnw50fmb-JyHVpDv5ermkVpS1X_hK7qv1MnZHYM1Hlo6zi7EAeSds2oBevMaSj0F80irBSF9DdMR6CDt7teL2aumIZy_wb2eFD0uLxDMQ==). The survey invitation, with background information, is below.

#### **INVITATION TO PARTICIPATE**

In many states the number of recommended newborn screens are being expanded. This has implications for the number of patients seen in your practices and the coordination of care for these patients. We need your help to understand how these changes will affect your practice.

Last year, the New England Genetics Collaborative conducted in-depth interviews with providers who treat patients with metabolic disorders identifiable by newborn screen in the New England region to examine the depth and scope of care provided, coordination of care, and provider perceptions about the impact of expanded newborn screening for metabolic disorders. Highlighted within our finding were:

- Care coordination needs improving. Providers are engaging in a variety of roles with patients and their families.
- Extra-care activities, such as educating families and working with insurers, are time consuming and rarely reimbursed.
- Expanded screening will likely exacerbate these issues without some fundamental changes to how care is delivered.

We invite you to view the full report at: [http://r20.rs6.net/tn.jsp?llr=ofyp6xbab&et=1107905631693&s=7901&e=001jxE0h5Q5VBfYJKY6upgT3hiSuuMZ4P0tX2sF1Lc8PVKFyE-cnp66EUygZ8GOXOYyJbF-hOqSPzNp\\_ImiOsUUN0fZKwo8EoBO13hkPzWq0QZepvtqbquS6XrFFPCnRJLTeURnKD0tRz1362b2oOe72mXajdZ7iyHf5mTuloETlz6HmdZqoDnur MPCWMOJYUXmyTlwy-00sOI6U04xMh9wQ==](http://r20.rs6.net/tn.jsp?llr=ofyp6xbab&et=1107905631693&s=7901&e=001jxE0h5Q5VBfYJKY6upgT3hiSuuMZ4P0tX2sF1Lc8PVKFyE-cnp66EUygZ8GOXOYyJbF-hOqSPzNp_ImiOsUUN0fZKwo8EoBO13hkPzWq0QZepvtqbquS6XrFFPCnRJLTeURnKD0tRz1362b2oOe72mXajdZ7iyHf5mTuloETlz6HmdZqoDnur MPCWMOJYUXmyTlwy-00sOI6U04xMh9wQ==)

These findings are only the first step in collecting empirical information on our field that will be valuable to the current and ongoing policy discussions affecting all of us. Now we are requesting your help.

To better understand what providers face nationally, we are asking you to complete a short on-line national survey regarding your experiences caring for children with metabolic conditions. The survey was developed with the University of New Hampshire Survey Center with funding from the National Coordinating Center for the Regional Genetic and Newborn Screening Service Collaboratives (NCC). You can access the survey by clicking on the following link or by copying and pasting it into the URL line of your browser: [http://r20.rs6.net/tn.jsp?llr=ofyp6xbab&et=1107905631693&s=7901&e=001jxE0h5Q5VBfYJKY6upgT3hiSuuMZ4P0tX2sF1Lc8PVKFyE-cnp66EUygZ8GOXOYyJbF-hOqSPzNp\\_ImiOsUUN0fZKwo8EoBO13hkPzWq0QZepvtqbquS6XrFFPCnRJLTeURnKD0tRz1362b2oOe72mXajdZ7iyHf5mTuloETlz6HmdZqoDnur MPCWMOJYUXmyTlwy-00sOI6U04xMh9wQ==](http://r20.rs6.net/tn.jsp?llr=ofyp6xbab&et=1107905631693&s=7901&e=001jxE0h5Q5VBfYJKY6upgT3hiSuuMZ4P0tX2sF1Lc8PVKFyE-cnp66EUygZ8GOXOYyJbF-hOqSPzNp_ImiOsUUN0fZKwo8EoBO13hkPzWq0QZepvtqbquS6XrFFPCnRJLTeURnKD0tRz1362b2oOe72mXajdZ7iyHf5mTuloETlz6HmdZqoDnur MPCWMOJYUXmyTlwy-00sOI6U04xMh9wQ==).

Thank you for taking time out of your busy professional lives to help impact future discussions and policy directions in genetic medicine.

For questions on this survey please contact:  
Robert J. McGrath, PhD  
University of New Hampshire  
Department of Health Management and Policy  
(603) 862-5047  
[Robert.McGrath@unh.edu](mailto:Robert.McGrath@unh.edu)

#### NCHPEG Poster Presentation

Also in September, Liza Creel, MSGRCC Project Manager, presented a poster at the 14<sup>th</sup> Annual Meeting of the National Coalition for Health Professional Education in Genetics. The poster, titled Use of Telemedicine to Deliver Genetics Education in Two Regional Genetics Collaboratives, described two telemedicine projects, one in the MSGRCC and one in the Heartland Region, that are utilizing telemedicine to deliver both clinical genetic services and professional education opportunities. The presentation authors were Liza Creel, MPH (MSGRCC), Shobana Kubendren, MS (University of Kansas School of Medicine - Wichita), Susan Landgren, MS (Billings Clinic), Celia Kaye, MD, PhD (MSGRCC), Joyce Hooker (MSGRCC), and Brad Schaefer, MD (University of Arkansas for Medical Sciences).



#### MSGRCC Announces Associate Project Director Position Opening

I am happy to announce our recruitment of an associate project director for MSGRCC. I have had the pleasure of serving as MSGRCC Project Director for the past three years, and I will continue in this role going forward. At its July meeting, our MSGRCC Advisory Council identified a need to broaden our leadership group. We seek an additional leader to reach out to our membership, and to plan and implement policies and programs. You can find the job description for this position at [http://r20.rs6.net/tn.jsp?llr=ofyp6xbab&et=1107905631693&s=7901&e=001jxE0h5Q5VBfYJKY6upgT3hiSuuMZ4P0tX2sF1Lc8PVKFyE-cnp66EUygZ8GOXOYyJbF-hOqSPzNp\\_ImiOsUUN0fZKwo8EoBO13hkPzWq0QZepvtqbquS6XrFFPCnRJLTeURnKD0tRz1362b2oOe72mXajdZ7iyHf5mTuloETlz6HmdZqoDnur MPCWMOJYUXmyTlwy-00sOI6U04xMh9wQ==](http://r20.rs6.net/tn.jsp?llr=ofyp6xbab&et=1107905631693&s=7901&e=001jxE0h5Q5VBfYJKY6upgT3hiSuuMZ4P0tX2sF1Lc8PVKFyE-cnp66EUygZ8GOXOYyJbF-hOqSPzNp_ImiOsUUN0fZKwo8EoBO13hkPzWq0QZepvtqbquS6XrFFPCnRJLTeURnKD0tRz1362b2oOe72mXajdZ7iyHf5mTuloETlz6HmdZqoDnur MPCWMOJYUXmyTlwy-00sOI6U04xMh9wQ==). Please review it, see if it applies to you, and consider whether you or a colleague would like to apply. We're looking for your ideas, energy, and commitment to our region.

As the days grow shorter and the evenings cool, our workgroups are busy with the plans they made at the MSGRCC annual meeting in July. Next month we'll include minutes from the workgroup meetings with this message, plus updates from each of them. Meanwhile, enjoy some cider and doughnuts!

Warm regards,

*Celia I. Kaye*

**Celia I. Kaye**, M.D., Ph.D.  
Project Director, MSGRCC

*MSGRCC staff contact information:*

**Celia Kaye**, Project Director, MSGRCC - [Celia.Kaye@ucdenver.edu](mailto:Celia.Kaye@ucdenver.edu)

**Joyce Hooker**, Project Manager, MSGRCC - [jhooker@msggcc.org](mailto:jhooker@msggcc.org) &  
303-978-0125

**Liza Creel**, Project Coordinator, MSGRCC - [lcreel@msggcc.org](mailto:lcreel@msggcc.org) &  
512-279-3906

Website: [http://r20.rs6.net/tn.jsp?llr=ofyp6xbab&et=1105758046034&s=7901&e=001SONIGE6UXeQWXHFcQjuMGAD5QP68k2wLFLWdUH9boYtar\\_k3T0hWYDcOxwuefX1AhF5hvn0--1eqnhYX8Fh4GkLQgnNSymbA6FkKniBrs3qI0HMIZwdekKqriFPMb1K3v\\_B10604a0=](http://r20.rs6.net/tn.jsp?llr=ofyp6xbab&et=1105758046034&s=7901&e=001SONIGE6UXeQWXHFcQjuMGAD5QP68k2wLFLWdUH9boYtar_k3T0hWYDcOxwuefX1AhF5hvn0--1eqnhYX8Fh4GkLQgnNSymbA6FkKniBrs3qI0HMIZwdekKqriFPMb1K3v_B10604a0=)

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Mountain States Genetics Regional Collaborative Center | 8501 North MoPac Expressway | Suite 300 | Austin | TX | 78759