



Message from the Project Directors Celia I. Kaye, MD, PhD & Kathryn Hassell, MD

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August 2012

Greetings!

Despite the continued heat and dry weather in most of our states, summer is almost over, families are back from vacation, and children have gone back to school. We hope you had some well deserved time off and are returning refreshed, if not cool.

Here in the MSGRC office, our team is still working to confirm dates for this year's Annual Meeting. You can expect to hear from us regarding the meeting dates over the coming weeks. The meeting will most likely be held in mid-Spring 2013. We sincerely apologize for the delays in setting the dates but our goal is to avoid as many conflicting professional meetings as possible. We know you depend on advance notice to get your travel approved, and we are doing everything possible to confirm these dates.

Over the next few Monthly Messages we will introduce you to some of the new projects MSGRC is supporting in the new grant cycle. This month, we'd like to tell you about the Hemoglobinopathies Long-term Follow-up Mini-Project. We begin by telling you about the history of hemoglobinopathies projects in the Mountain States and then describing the new project.

History of Hemoglobinopathies Projects in the Mountain States

MSGRC has supported projects related to sickle cell disease and trait since 2005. The first project, led by Kathryn Hassell, MD at the Colorado Sickle Cell Center, focused on finding communities at risk for sickle cell disease and identified an emergent Hispanic population in Colorado. A subsequent project, "Implementation of Genetic Counseling Services Through Community Public Health Clinics: Sickle Cell Trait Pilot Project", piloted the provision of free genetic counseling and laboratory testing for families of infants identified with sickle cell trait by newborn

screening in Colorado, in an effort to reach emergent and traditional communities.

In 2007, MSGRC established the Hemoglobinopathies Interest Group to conduct the "Regional Standardization of Newborn Screening Follow-Up: Hemoglobinopathies and Sickle Cell Trait" project (Kathryn Hassell, MD, Project Director). Each state in the region has been represented; members include representatives of primary and specialty care, state departments of health NBS follow-up personnel, community-based organizations and consumers. During this project it was established that all states offer services to families of infants identified with any form of hemoglobinopathy, including sickle cell disease. Notification of providers, if not always families, also occurs when sickle cell trait is identified. Information contributed by the group also confirmed that sickle cell trait and disease occurs in diverse communities in our region. Data from five states (Colorado, Wyoming, Utah, Arizona and New Mexico) from years 2002 and 2008 are summarized in the table below:

Race/Ethnicity of Infants with Sickle Cell Trait	Number (%)
Black (+Other, Hispanic/Non-Hispanic)	773 (43.3%)
Non-Black, Hispanic	515 (28.9%)
Non-Black, Non-Hispanic/Unknown	318 (17.8%)
White	232 (13.0%)
Native American	16 (0.9%)
Asian	7 (0.4%)
Other/Unknown	63 (3.5%)
Unknown	179 (10.0%)

The Hemoglobinopathies Long-term Follow-up Mini-Project

Although all states in the region provide consistent, high-quality NBS and short-term follow-up services, only three states attempt long-term follow-up of hemoglobinopathies. Furthermore, there is no systematic assessment of access to a culturally-appropriate medical home with knowledgeable medical providers for individuals and families with hemoglobinopathies.

During this grant cycle, MSGRC will fund the evolution of this work through the Hemoglobinopathies Long-term Follow-up Mini-Project. During the first year, this project will identify sites of health care for people with hemoglobinopathies, exploring strategies for surveillance and long-term follow-up; assess support needed to serve individuals with hemoglobinopathies, and dissemination of information; establish a centralized resource on the MSGRC website, with information regarding medical homes, links to state DOH and other resource/educational websites; and provide a point of contact to reach hemoglobinopathies experts for questions/referrals. We will also facilitate distance strategies including telemedicine.

MSGRC is excited about the opportunity to contribute to advances in long-term follow-up for individuals with hemoglobinopathies. This

work will inform best and feasible approaches to long-term follow-up for many other disorders. For more information about the project, please contact Kathryn Hassell, MD at Kathryn.Hassell@ucdenver.edu.

MSGRC Communications Survey

Don't forget to complete the MSGRC communications survey, which can be found [here](#) (or paste this link into your browser: <https://www.surveymonkey.com/s/33ZL6PV>). We are interested in understanding your preferences for participating in virtual meetings and conference calls. Please take a few moments to complete the short survey. MSGRC will use your feedback to schedule events for the remainder of the grant year.

MSGRC Program Evaluation RFP

We recently posted a Request for Proposals (RFP) for an evaluation contractor to design and implement a five-year evaluation of the Mountain States Genetics Regional Collaborative (MSGRC). The RFP can be downloaded [here](#) (or paste this link into your browser: http://www.msgrcc.org/files/MSGRC_Evaluation_RFP_final_082912.pdf

If you have experience in program evaluation and may be interested in submitting a proposal, please take a moment to review the RFP. Also, please share with your evaluation colleagues. All questions should be directed to Sherry Wilkie-Conway at swilkie@texashealthinstitute.org, with an email subject of "RFP Evaluation Contractor Question".

And now, we hope you're planning something enjoyable for this last official week-end of the summer. If you have a chance to take a snapshot of yourself, please send it along. One of us (Celia) is interested in creating a gallery of our members, and I don't want to see you working!

Warm regards,



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

Kathryn Hassell, M.D.
Associate Project

MSGRCC staff contact information:

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

Kathryn Hassell, Associate Project Director, MSGRCC -
[mailto:Kathryn.Hassell@ucdenver.edu?](mailto:Kathryn.Hassell@ucdenver.edu)

Joyce Hooker, Director of Regional Outreach, MSGRCC -
[mailto:jhooker@msgrcc.org?](mailto:jhooker@msgrcc.org) &
303-978-0125

Liza Creel, Project Manager, MSGRCC - <mailto:lcreel@msgbcc.org?> &
512-279-3906

Website: <http://www.mountainstatesgenetics.org/>

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