



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

**Join Our List.**

[Join Our Mailing List!](#)

**November 2014**

Greetings,

Thanksgiving may have passed, but here at MSGRC we continue to be thankful. Our region has seen many recent successes due in large part to the continued efforts of all of our partners. With the year's end rapidly approaching, we thought this an ideal time to highlight achievements of many of our states in newborn screening (NBS) timeliness in 2014.

### **Newborn Screening Timeliness: Success in Our Region**

Our September message centered on the discussion on timeliness of NBS at the last meeting of the Secretary's Discretionary Advisory Committee on Heritable Disorders in Newborns and Children (SDACHDNC). Recommendations are currently being reviewed which include collection of the initial blood spot (DBS) sample at 24-48 hours, receipt of the DBS sample in the newborn screening laboratory within 24 hours of collection, reporting of time critical conditions by five days of life, and reporting of all results within five days after initial collection. The Association of Public Health Laboratories (APHL) had previously distributed a survey and received responses from all 50 states. Preliminary results showed that none of these recommendations were currently being met for all babies screened in the US.

In response to the recent SDACHDNC meeting, MSGRC's NBS workgroup recently convened in a full workgroup webinar focused on the subject of timeliness. Our goal was

to employ a constructive approach to recognize what improvements have been achieved by states in our region in recent years. State health department representatives from Arizona, Colorado, Utah, and Texas all had notable successes to share with the group. The presentations can be accessed on the MSGRC website [NBS Workgroup page](#).

Highlights from our presenters included:

**Sondi Aponte, Quality Improvement, Education & Outreach Manager, Office of Newborn Screening, Arizona:**

AZ was specifically mentioned in a 2013 Journal Sentinel Watchdog Report as having one of the worst track records in the country. AZ saw this as an opportunity for improvement and set a goal in January 2014 to have 95% of all initial DBS samples to the state lab within three days of collection. A new statewide courier program was launched that included pickup and delivery Monday through Saturday and same or next business day delivery. By September 2014, 99% of initial screens arrived to the state lab within one day of collection, far surpassing the original goal.

**Erica Wright, MS, CGC, NBS Follow-up Supervisor, Colorado:**

A collaborative workgroup was formed which included representatives from the state lab, Colorado Hospital Association (CHA), and birthing facilities in the state. Their goal was to reduce total time from birth to completion of NBS. The three workgroup subcommittees included Education, Transport, and IT. A pilot project was initiated in several hospitals for September 2014 through December 2014 in which the state lab is monitoring quality indicators and turnaround times. Outcomes will be assessed in February 2015. Successes will be shared with birthing centers throughout CO and used to develop further recommendations to support NBS timeliness.

**Brendan Reilly, Program Specialist, Newborn Screening Laboratory, Texas:**

The TX Newborn Screening Performance Measures Project was initiated in Sept. 2007. The goals of this project were to reach 100% for four measurements: 1) satisfactory specimens 2) collection between 24-48 hours 3) receipt within 72 hours from collection 4) submission of all key demographic information. Healthcare facilities were given education in the form of educational inserts, onsite presentations, online resources, and other feedback. A courier pilot project started in 2010 showed a dramatic increase in 1<sup>st</sup> screen specimens received under three days. The pilot was expanded in 2012. Monthly follow-up has been initiated at the ten facilities with the highest volume of delayed specimens. This follow-up has shown success in decreasing

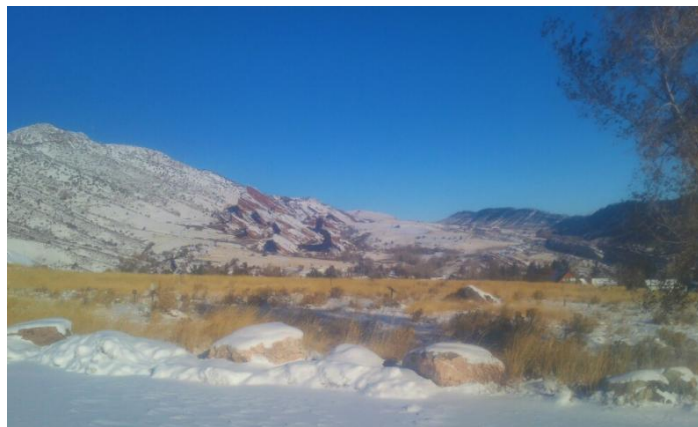
delays. Future goals include continuing outreach activities and expanding courier services to all sites.

**Dr. Andy Rohrwasser, PhD, MBA, Newborn Screening Director, Utah:** An important step in UT was to view NBS (sample receiving, lab, follow-up, IT) as a system. While sample testing and follow-up were close to capacity, or the optimum efficiency, sample collection and receiving were identified as areas that could be improved. In October 2014, Utah implemented use of FedEx in the poorest performing hospitals, those that took over three days to be received at the state lab. So far, this investment has shown success and transit time is currently under three days, a significant decrease.

### Recent Meetings

The **Hemoglobinopathies Long-Term Follow-up Workgroup** convened on November 17, 2014 in Denver, CO. Even with brisk temperatures and snow, we were pleased to have representatives from all states in our region from a variety of backgrounds including practitioners, health department staff, and consumers.

The group discussed protocols in different states on NBS follow-up for Sickle Cell Disease (SCD). The group also reviewed the recent National Heart, Lung, and Blood Institute (NHLBI) guidelines on SCD and considered how this information might best be disseminated in our region and nationally to both providers and families. Another focus of this group continues to be long-term outcomes of SCD patients and closing gaps in services for adult patients. An "action item" list was produced at the meeting that will be integral in meeting many of the objectives identified by this workgroup.



A view from Morrison, CO, only 18 miles west of Denver, CO.

**The NCC Project Director/Project Manager Annual Meeting** was held in Washington DC from November 6-7.

While we may only be half way through our current 5-year grant cycle, there is much interest in what direction the regional collaboratives will take in future years. Several sessions at the annual meeting were devoted to developing the future vision for the regional collaboratives. Further focus on access to genetic services is expected to be a priority in the future.

### Closing Thoughts

As winter approaches, the days are quickly becoming cooler for all. This time of year highlights the wonderful diversity that exists within our region. Whether spent surrounded by green grass, desert landscapes, or snow-capped mountain ranges, we wish everyone a wonderful December full of holiday cheer.

Warm regards,

Handwritten signature of Celia I. Kaye in black ink.

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

Handwritten signature of Kathryn Hassell in black ink.

Kathryn Hassell, M.D.  
Associate Project Director

**MSGRC staff contact information:**

Celia Kaye, Project Director

[Celia.Kaye@ucdenver.edu](mailto:Celia.Kaye@ucdenver.edu)

Kathryn Hassell, Associate Project Director

[Kathryn.Hassell@ucdenver.edu](mailto:Kathryn.Hassell@ucdenver.edu)

Joyce Hooker, Director of Regional Outreach

[jhooker@msggcc.org](mailto:jhooker@msggcc.org) Â·303-978-0125

Marilyn Brown, Project Manager

[mbrown@mountainstatesgenetics.org](mailto:mbrown@mountainstatesgenetics.org) Â·512-279-3919

Kristi Wees, Social Media Coordinator

[kwees@mountainstatesgenetics.org](mailto:kwees@mountainstatesgenetics.org)

Website: [www.MountainStatesGenetics.org](http://www.MountainStatesGenetics.org)

**[Forward email](#)**



This email was sent to pauline@hawaiiigenetics.org by [mbrown@mountainstatesgenetics.org](mailto:mbrown@mountainstatesgenetics.org) | [Update Profile/Email Address](#) | Rapid removal with [SafeUnsubscribe™](#) | [Privacy Policy](#).



Try it FREE today.

Mountain States Genetics Regional Collaborative | 8501 North MoPac Expressway | Suite 170 | Austin | TX | 78759