



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

May, 2011

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Greetings!

This has been a month of spring flooding for the mid-section of our country, as the Mississippi River proves again that Nature has surprises for us. Here in the Mountain States, we're waiting for the melt of the heavy snow pack that delighted winter skiers. At MSGRCC, we feel something like the recipients of all that lovely spring water - we're refreshed by new resources and challenged to make the most of what we have.

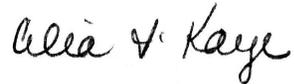
During the month of May, MSGRCC staff attended the May 5-6 meeting of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) in Washington, DC. SACHDNC has been reviewing evidence for addition of critical cyanotic congenital heart disease (CCCHD) and hyperbilirubinemia to the recommended panel for newborn screening. At this meeting, SACHDNC received a response from Health and Human Services Secretary Kathleen Sebelius to their October 15, 2010 recommendation that CCCHD be added to the recommended panel. In their recommendation, SACHDNC noted evidence gaps and therefore also recommended activities by NIH, CDC and HRSA to address those gaps. In her response, Secretary Sebelius concluded that the SACHDNC recommendation is not ready for adoption. Instead, the SACHDNC recommendation was referred to the newly established Interagency Coordinating Committee on Newborn and Child Screening (ICC) for additional review and input regarding implementation. The ICC includes membership from the NIH, CDC, HRSA, the Agency for Healthcare Research and Quality (AHRQ), and the FDA. The ICC leadership will examine the evidence gaps and propose a plan of action to the Secretary within 90 days.

Also at SACHDNC, evidence for addition of hyperbilirubinemia to the recommended panel was reviewed. It was noted that indirect evidence links a reduction in hyperbilirubinemia to reduced incidence of kernicterus (chronic bilirubin encephalopathy), but the incremental benefit of adding newborn screening to current practice is not known. The committee concluded that additional work by the evidence review committee, including developing a decision tree model for the screening, should be done before a recommendation is considered. SACHDNC also reviewed state pilots of implementation of newborn screening for severe combined immunodeficiency (SCID). Currently, there are pilots in California, Louisiana, Massachusetts, New York, Puerto Rico, Wisconsin, and on the Navajo Reservation in Arizona and New Mexico. In our region, Texas is submitting samples to the Massachusetts pilot. Since 2001 and through these pilots, 914,000 babies have been screened for SCID. Of those, 12 have been identified with classical SCID (incidence of 1/76,000), seven with a SCID variant (incidence of 1/130,000), and 55 with non-SCID immunodeficiency (incidence of 1/126,000). Early findings show that incidence is generally higher than expected, but also variable among states. The Centers for Disease Control and Prevention has also implemented a quality assurance program with reference materials for laboratory testing, and since April 2011, participants are seeing very high analytic validity and specificity. Finally, a new data portal for SCID has been developed through the Newborn Screening Translational Research Network (NBSTRN) and deidentified data are being submitted.

MSGRCC staff is finalizing arrangements for our annual meeting July 12-14 in Denver. Our keynote speaker, Meg Comeau from the Catalyst Center at Boston University, will speak about the Affordable Care Act and its impact on children with special health care needs. Dr. Rodney Howell, chair of the SACHDNC, will also present on recent activities supported by the SACHDNC. Click [here](#) for the Annual Meeting agenda and to find registration information.

As we prepare for summer activities, we hope you will continue to let us know how MSGRCC can help you in your efforts to improve access and quality of services for newborn screening and genetics in your state and/or neighborhood. Bring your ideas and issues to the annual meeting in July. We want to talk to you about how we can work together even more closely to meet our common goals.

Warm regards,



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

MSGRCC staff contact information:

Celia Kaye, Project Director, MSGRCC - Celia.Kaye@ucdenver.edu
Joyce Hooker, Project Manager, MSGRCC - jhooker@msggcc.org &
303-978-0125

Liza Creel, Project Coordinator, MSGRCC - lcreel@msggcc.org &
512-279-3906

Website: <http://r20.rs6.net/tn.jsp?>

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