



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

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February, 2012

Greetings!

Valentine's Day is behind us, and we hope you enjoyed a little chocolate and some time with the people you love best. St. Patrick's Day is ahead, and when Celia thinks of that day, she remembers the Chicago River, dyed green for the day, and the parade that celebrated a culture and a community.

Please mark your calendars for the MSGRCC 2012 Annual Meeting, which will be June 28-30 in Denver, Colorado. The hotel and meeting location are being finalized and we will share those details with you as soon as they are available. In addition to continuing the valuable activities of each of our workgroups, we will have plenary sessions on relevant genetics and newborn screening topics, and several project meetings. We hope to see you there!

Beautiful Phoenix was the host city for the MSGRCC mid-year workgroup meetings February 24-26. MSGRCC staff and many of you enjoyed three days of productive work and networking. We will be posting the minutes of the workgroup meetings on our website.

The Newborn Screening Workgroup, chaired by Susan Tanksley (TX) and Jeff Botkin (UT), who participated by phone/webinar, heard updates from each state, including status reports on implementation of newborn screening for Severe Combined Immunodeficiency Disorder (SCID) and Critical Cyanotic Congenital Heart Disease (CCCHD); status of data integration; and implementation of NICU newborn screening protocols. Jeff Botkin, who is a member of the Secretary's Advisory Committee on Heritable Disorders in Newborn and Children, provided a report on the activities of the committee at their January meeting. Stuart Shapira

from CDC gave a preliminary report on a retrospective study of second newborn screens for congenital hypothyroidism and congenital adrenal hyperplasia. The workgroup will consider some reorganization to allow increased focus on specific issues by smaller subgroups. They will also work to resolve follow-up issues in states who contract with other states for nbs laboratory services.

The Advisory Council met to review activities of the current year as well as plans for the next five years, as reflected in the grant submitted recently to HRSA for competitive continuation of MSGRCC. As always, they provided us with great perspective and guidance, and will remain critical partners as MSGRCC grows over the coming years.

The Emergency Preparedness Workgroup, chaired by Donna Williams (TX) and Sondi Aponte (AZ), reviewed emergency preparedness activities in each of the states. Activities in most states have concentrated on newborn screening laboratory preparedness, with some emphasis also on short term follow-up. However, there has been no focus on emergency preparedness from the standpoint of the individual family. At this meeting, families and workgroup members talked through the steps that are needed to assure that families are prepared for emergencies that could interrupt their access to medical foods, specialty providers, essential medications, equipment, and other necessities. This will be the focus of the workgroup for the next year.

The Telemedicine Workgroup, chaired by Brad Thompson (TX) and Thelma McClosky Armstrong (MT), reviewed our current telemedicine projects (the Colorado Early Hearing Detection and Intervention Telemedicine Project; the Montana Tele-genetics Project), two new projects (Cook Children's Telegenetics Program; Telemedicine in Native American Communities) and proposals for the coming grant cycle. This workgroup will work on the development of a basic dataset to be collected from each telemedicine project and will complete a white paper on telemedicine and the medical home.

The Consumer Advocacy Workgroup, chaired by Joe Martinec (TX) and Rod Slaght (CO), reviewed many of the MSGRCC projects and discussed their sponsored presentation for the MSGRCC 2012 Annual Meeting. Dr. Sydney Rice presented on the Arizona LEND (Leadership Education in Neurodevelopmental and Related Disabilities) program, and there was discussion about strategies for strengthening collaboration with the Arizona LEND and other valuable programs in the region. Finally, the workgroup suggested that MSGRCC consider implementing a mentorship program where long-standing Consumer

Advocacy Workgroup members can mentor new consumer advocates in the region.

This was a wonderful 3 days, as we celebrated all that has been done over the last 4 years and our plans for the future. We were humbled by the commitment and volunteer spirit of our friends and colleagues. Most of our members attend these meetings on their own time, and they spend numerous hours in between meetings working on various workgroup projects. Over these three days, members identified new priorities, talked about what they can do to overcome barriers, and volunteered yet again to do more on behalf of their children, patients, neighbors, friends, and complete strangers. We live in a fairly cynical time, but this meeting put cynicism to the test. We were left with faith in the good will and determination of people who just want to make things better. Thanks to all of you who were in Phoenix or contributed to the discussion via teleconference and webinar, and thanks to those who support us but were unable to be there this time.

Warm regards,

 

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