



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

July, 2011

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Greetings!

July was a month of celebration for us as we welcomed many of you, as well as guests from around the country, to the MSGRCC annual meeting in Denver. More than 75 individuals participated in the annual meeting; we all learned from the keynote address on the impact of healthcare reform on genetic services, and we appreciated updates from our federal partners at HRSA, SACHDNC and the NCC. In addition, all workgroups met, several projects had their annual meetings, and many of us participated in a tabletop exercise on emergency preparedness. The MSGRCC Advisory Council met for a strategic planning session which will guide our competitive renewal application this fall. And of course we shared stories about the challenges in our professional lives and enjoyed just catching up with good friends. We'll provide more details about the meeting in the next Message from the PD.

The Genetic Services Branch (GSB) at HRSA announced in July that our good friend and Chief of GSB, Michele Lloyd-Puryear, MD, PhD, is leaving HRSA to take a position as Expert in Genetics and Newborn Screening Services in the Office of Rare Diseases at the NIH. Michele has been an outstanding leader and advocate for genetics at GSB, and she has been a very good friend to MSGRCC. We will miss her! The good news is that Sara Copeland, MD, has been appointed as Acting Chief of GSB. Sara has been with GSB for 18 months; she is an experienced metabolic pediatrician with extensive expertise in public health and newborn screening. She will provide a very steady hand during this period of transition, and we are looking forward to working with her very closely in the future.

This month we'd like to share with you the final version of "The Life Rope: Engagement of Diverse Populations for Recruitment and Representation in Genetics," a white paper prepared by the MSGRCC Consumer Advocacy workgroup. Our staff have spent time over the last year presenting the white paper to the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children Education and Training Subcommittee, other regional collaboratives on a monthly National Coordinating Center conference call, and at the Academy for Health Equity 2010 Annual Conference. You've probably heard us talk about the white paper many times and now you can see the full version (and share it with your colleagues!). You can find the complete paper at http://r20.rs6.net/tn.jsp?lr=ofvp6xbab&et=1106920865182&s=7901&e=001n70drSD1smY9qDrPTPsZa5UzcZ5Q50q70IMOiSquQ_vmjSmVe5AViPqrE5SLPaMPBCaAC297nan2847TCpy3O8qb9I9JfRBQSIzHE0AicTfF1OXsQaaKNWO4fXpHel95_n_MhSmySBtQkc0q_AJfBjSxPldxKQqaFK_6xpnfj2ublzgz0Q==.

As August provides all of us with plenty of heat, I hope you take some time to enjoy these late summer days. I can imagine you sitting on your porch or balcony, sipping something cool, and letting your mind wander to thoughts of your favorite things. That's what I'll be doing!

Warm regards,

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

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