



Message from the Project Directors Kathryn Hassell, MD & Janet Thomas, MD

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December 2015

Even with the busy holidays upon us, there have been several year-end activities as we plan for 2016. Please read on as input from our colleagues and partners throughout the region is needed!

NCC 2015 Meeting

The MSGRC team (Kathy, Janet, Sharon, Marilyn, and Joyce) recently attended the National Coordinating Center (NCC) Project Director/ Project Manager in Washington, DC on November 12-13. Representatives from the regional collaboratives (RCs) and partner organizations from across the country were in attendance to discuss both our current projects and future directions for the RCs.

The meeting began with a review of the national provider and consumer surveys. For genetic services providers, education and genetic consultations for non-genetics providers, technical assistance, and standardized genetic services were all noted as high priority. Consumers identified difficulty of finding information on providers with condition-specific expertise and other support services. They also had difficulty obtaining appointments with specialist and indicated that the most useful service would be scheduling assistance and appointment reminders.

The information collected through the surveys was key in discussions on Regional Support Service Center Models (RSSM) and Patient Navigator Models. The RSSM Workgroup, led by Celia Kaye, has been actively reviewing

existing models, many that are condition-specific. Members of the RSSM Workgroup will be meeting again this December to conceptualize how the RCs can operate as a support service model. As always, MSGRC will keep our stakeholder informed of key outcomes.



From (L) to (R): Debbie Maiese (NCC), Joyce Hooker (MSGRC), Marilyn Brown (MSGRC), Karen Smith (NEGC) enjoy a quick trip to the White House in-between meetings.

MSGRC Focus Group Meetings

As MSGRC evaluates how the Regional Support Service Center Model (RSSM) can best support providers and patients in our region, feedback from our stakeholders is key. MSGRC will be holding **In-person Focus Groups January 27-29, 2016**, in Las Vegas, Nevada. This meeting will help us do much of the groundwork for our **2016 Annual Meeting, April 14-16**, in Phoenix, Arizona. Meetings will focus on provider, consumer, and public health issues that can be addressed through the development of the RSSM. **The expertise of those practicing in both primary care and genetics is especially needed. If interested in participating in a Focus Group, please contact Marilyn Brown (mbrown@mountainstatesgenetics.org).** MSGRC will be able to provide travel support for approved Focus Group members. We hope to see all of our Workgroup Members at our April 2016 Annual Meeting!

Other Activities

- Recordings from the November Advisory's Committee on Heritable Disorders in Newborns and Children (ACHDNC) Webinar Meeting can now be accessed [online](#).
- The 60-day notice for the MCHB proposed Discretionary Grant Performance Measures has been released. We encourage all stakeholders to access the Federal Register Notice (FRN) and the Performance Measures draft instrument through this [link](#). Public comment closes on January 5, 2016.
- MSGRC is excited to announce the 2016 Health Resources and Services Administration (HRSA) Regional Collaborative (RC) Advocate Leaders Partnership Program. Up to two consumer leaders from each region will be awarded support to attend the ACMG Annual Clinical Genetics Meeting in March 8-12, 2016. This year it will be in sunny Tampa Florida. Please follow the links for [information](#) and the [application](#). Contact Marilyn Brown (mbrown@mountainstatesgenetics.org) if interested!
- Again, please mark your calendars for the MSGRC Annual Meeting, April 14-16, 2016!

Final Thoughts

We wish much joy for everyone as Christmas and New Year's fast approaches. As we approach 2016, we hope to continue to serve the needs of providers, consumers, and other stakeholders in the MSGRC region.

Warm regards,



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