



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

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January 2016

You may remember that the MSGRC ended 2015 immersed in the final planning of the In-person Focus Groups in January 27-29, 2016. As promised, we have much to report regarding the meeting which was a wonderful success thanks to the engagement of our attendees.

MSGRC Focus Groups

Approximately fifty attendees from our region's eight states attended and we were excited to host a diverse representation of consumers, clinicians, and public health professionals. We kicked off the meeting with our consumer dinner, where consumers, including many new to MSGRC, were oriented to some of MSGRC's recent work and share their stories of what brought them to MSGRC. The dinner was a nice commencement to the following two days of consumer and provider/public health focus group meetings.

On Thursday, we reconvened for the consumer-oriented focus groups. We were able to directly hear from consumers and families with complex backgrounds and healthcare needs on topics of care coordination, referral to specialty care and social support services, social and health inequities, and other areas of interest. Thursday afternoon, had our members of all backgrounds (consumer, clinician, public health) working together to rank genetic priorities in our region. After discussion in small groups, members were able to "vote" with poker chips on what they saw as priority needs. Family support (patient navigators, advocacy), consultation/resources for non-genetics providers, technical support, and telemedicine were some of the top priorities identified.

Our clinician and public health session, hosted Friday, began with a expert panel of public health leaders Debbie Freedenberg (TX), Sondi Aponte (AZ), and Carleigh Soule (WY) that gave our attendees a better understanding on current capacities and needs from a public health perspective. We closed with a discussion on what resources clinicians needed to better serve patient needs and also more efficiently see patients.

The Focus Group Meetings afforded us a unique opportunity as a region to collectively evaluate the current genetics landscape, what gaps are present currently and likely to exist in the future, and how MSGRC can develop resources that will address the needs of our stakeholders. Detailed notes and other resources from the Focus Group meetings will be available soon at <http://www.msgrcc.org/events/events.html>.

Upcoming ACHDNC Meeting

The next Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) is scheduled for February 11-12, 2016 and will be held in-person and via webcast. Some of the meeting topics will include:

- panel discussion on Long Term Follow-up activities regarding newborns and children identified via NBS
- updates from workgroups (cost analysis in NBS, NBS timeliness, and pilot studies for future nominated conditions)
- discussion of proposed priorities and action items from the three subcommittees (lab standards and procedures, follow-up and treatment, and education and training) to develop a plan for 2016

Please follow the link to attend in-person or via webinar!

<https://www.blsm meetings.net/ACHDNCFebruary2016/registration.cfm>

Family Leadership Program

MSGRC is now accepting applications for the in-person Family Leadership Meeting on March 30-31st, 2016 in Washington DC. Please submit your complete application by February 22, 2016 to mbrown@mountainstatesgenetics.org. Please share this opportunity with anyone in the region that may be interested in attending!

Follow the link for more information:

http://www.familyvoices.org/admin/miscdocs/files/FV2016_Postcard_01-28-2016_Finalr.pdf

Final Thoughts

We want to thank everyone that was able to attend our Focus Groups. Your insight and expertise are invaluable as we plan how to move forward for this upcoming grant year and plan for our Annual Meeting in Phoenix, Arizona from April 14-16, 2016. Please be on the lookout for more information on our Annual Meeting in the upcoming weeks!

Warm regards,



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