



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

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July 2015

Time is certainly flying by for us at MSGRC as we balance work and travel as we prepare to enter our last full month of summer. Kathy and Janet were both out of the country for work and pleasure. Joyce is in Nova Scotia for the rest of summer enjoying coastal views and equine friends but continues to contribute to our work. We mentioned last month that we were in the midst of our annual evaluation for the National Coordinating Center (NCC). Although we are preparing for many programmatic changes over the next two years, we want to look back on our past accomplishments, many of which will continue to have broad impact in the future.

NCC Evaluation Report

MSGRC continued to use multiple venues (teleconference, webinar, in-person) to host 65 collaborative sessions with members, partners, and other genetics professionals. Our web and social media continues to be widely accessed with 10,582 encounters to date. Our Facebook page, managed by Consumer and MSGRC member Kristi Wees, received 7,959 unique visits as a result of her timely posts on medical home, newborn screening capacity, long term follow-up, collaboration, ACA implementation and transition from pediatric to adult care.

Members of our six workgroups (Consumer Advocacy, Newborn Screening, Telegenetics, Emergency Preparedness, Medical Home and Health Information Technology) continued to report high levels of effective collaboration (i.e. timely topics, strong structures, staffing

and membership, effective process and results achieved) in the annual Working Together Survey. Highlights of 2015-2016 included:

- Meetings and regional panel presentations to share effective practices for use in newborn screening labs, testing, testing access and data exchange;
- Based on 2014 Emergency Preparedness (EP) Surveys of Providers and Consumers, the EP Workgroup disseminated findings and recommendations concerning the unique needs of mountain and frontier communities in EP.
- Developing a mapping methodology and report describing genetics services shortage areas in the region, shared and disseminated this work with all of the Regional Collaboratives;
- Evaluated family health history tools for use in primary care practice (and exploring potential software vendor partners in developing HER-compatible tool); and
- Enhanced the networking and information-sharing among consumers in the Mountain States through the MSGRC Facebook, which provides credible, practical and difficult-to-find resources and information.

Our annual evaluation was a great reminder of what we have accomplished and how we can utilize our previous work in the development of a resource center model.

Upcoming Events

ACHDNC Meeting Announcement

The next in-person Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) will be held **August 27-28, 2015**. The meeting will also be available through broadcast. Participants attending in-person or by webcast must register by **Friday, August 21**. Items on the agenda include:

- a final evidence review report on Adrenoleukodystrophy (ALD) Nomination for inclusion on the RUSP
- a presentation by the Newborn Technical Assistance and Evaluation Program on their activities and data repository
- updates on the implementation of Severe Combined Immunodeficiency, Critical Congenital Heart Disease, and Pompe Disease

- updates from workgroups focused on cost analysis in newborn screening, newborn screening timeliness, and pilot studies for evidence based reviews of conditions
- Committee vote on recommendation to the Secretary for the addition of ALD to the RUSP

Further information on registration, webinar information, and public comments can be found [here](#).

Closing Thoughts

We anticipate fall will be busy and eventful as we initiate much of the plans we have formulated with our workgroups. For now though, we thought we would end with a photo of Joyce's friend and neighbor in Nova Scotia. While we miss having her here in Denver, we know she is enjoying the company of her four legged friends.



Warm regards,



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