



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

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**March 2017**

Dear friends and colleagues,

With just a couple short weeks left until Spring, MSGRC has important news to share. Registration for the MSGRC Annual Meeting is now open! We hope to see many of you in Salt Lake City from April 20-22. Please read on below for important information regarding the Annual Meeting and other activities in the genetics community.

### Upcoming MSGRC Annual Meeting

The MSGRC Annual Meeting, "*Seeds of Sustainability: Cultivating Genetics Across the Region*," will have many new features this year in addition to our workgroup sessions. As we draw close to the end of the current cycle, May 31, we want to use our Annual Meeting, as an opportunity to finish up current activities, re-engage and grow our membership base, and celebrate all of the great work that has been accomplished. To facilitate these goals, we will be featuring some of the below activities:

- New speakers from the other regional genetics collaboratives, the Southwest Telehealth Resource Center, and ACHDNC
- An evening networking session sponsored by PerkinElmer with beverages and light refreshments
- A dinner and movie night open to all with emphasis on consumer engagement
- Booths to visit from sponsoring companies

- The "Collaboration Cafe," which will provide a final venue for attendees to network and discuss meeting outcomes

For more details, the meeting agenda and all meeting details can be accessed [online](#). We ask that attendees complete [registration](#) and book flights by May 30 if possible. If you have any questions regarding attendance, please contact [Marilyn Brown](#). We will be able to cover travel expenses for all current members and those interesting in joining MSGRC as a new member. Please share this to any colleagues in the genetics community that reside in the MSGRC region.



#### **MSGRC Honors Rare Disease Day**

MSGRC would like to celebrate Rare Disease Day, which was February 28th. It is an honor for MSGRC to have our continued family engagement and many consumer members and leaders. Thank you for all that you do! Your input and leadership are vital to our continued success.



1 IN 10 AMERICANS ARE  
AFFECTED BY A  
**RARE DISEASE**-  
AND MORE THAN HALF  
ARE CHILDREN.

MSGRC HONORS RARE DISEASE DAY 2017  
ALONE WE ARE RARE,  
TOGETHER WE ARE STRONG



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### February ACHDNC Meeting

The ACHDNC recently convened via webinar, February 9.  
Items discussed included:

- US Government Accountability Office Report- NBS Timeliness
- NBS Cutoffs and Algorithms
- National Contingency Plan for NBS
- Workgroup Updates

All presentations and the webinar recording for the meeting are now available [online](#) through the HRSA website.

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### MSGRC Mapping Project Update

As many of our members may remember, the MSGRC completed a mapping project in 2015 that showed the geographic locations and sizes of genetics clinics and demographic information through surveys of our genetics clinics in the MSGRC region. In late 2016, MSGRC developed an expanded survey, to collect additional information on catchment areas and availability of outreach clinics and telemedicine. We would like to extend a sincere thank you to the many clinics in our region that have participated in our project. Our final reports and analysis are expected to yield important information on the availability and distribution of genetic services.

### Endings and Beginnings

This spring will bring many changes here at MSGRC. While the current cycle is almost completed, we will be continuing many important activities in the upcoming months. We also anticipate high attendance at our Annual Meeting. There will be many new members in attendance and we are excited to be hosting in Salt Lake City for the first time. We hope to see all of you there!

Warm regards,



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Project Director



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Associate Project Director

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