



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

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August 2015

As mentioned last month, MSGRC has been working with many of our Workgroup Co-Chairs as we continue to lay the groundwork for Needs Assessment in this current grant year. The MSGRC team also recently attended the Secretary's Advisory Committee on Heritable Disorders in Newborns (SACHDNC). Please read on for more information regarding important updates both at MSGRC and nationally.

MSGRC Co-Chair Discussion

Chairs from our five workgroups (Consumer Advocacy, Emergency Preparedness, Medical Home, Newborn Screening, Telegenetics) and special interest group (Health Information Technology) are working with MSGRC to provide guidance as we discuss both needs assessment and models for genetics resource centers that would address the needs in our region.

Discussion during our first webinar, led by Dr. Sharon Homan, focused on needs that are unique to our region. Our eight states are diverse; many of our states include wide, rural areas that are medically served or home to unique populations such as the Navajo Nations. MSGRC plans to fully utilize and build on existing resources such as social media (Facebook, MSGRC website) and our consumer connections (Genetic Alliance, Family Voices, impacted families) to determine how a resource center can best serve those affected by hereditary conditions.

Focus groups will also be held with the many leaders in public health and medicine who continue to commit their time to the progression of MSGRC and its reach. Agencies and organizations such as State Health Departments, American Academy of Pediatrics, American College of Medical Genetics) are valuable sources for both information and feedback as we use the remaining grant cycle to determine how to create sustainable resource centers that meet the needs of all of the groups we serve. Please follow this link to view the [presentation](#) by Dr. Sharon Homan that was used as a framework for discussion and planning.

ACHDNC Meeting Recap

Last month we mentioned that the MSGRC team would be attending the August ACHDNC meeting. Many items relevant to MSGRC members and stakeholders were addressed. Some of the highlight from the meeting are reported below:

- ACHDNC Workgroups: Pilot Study, Cost Analysis, and Timeliness are currently active; these workgroups will focus on the needs for nominated conditions to meet 9 month deadlines.
- NewSTEPS: Marci Song, PhD, from the Colorado School of Public Health presented on their efforts improve quality data collection and provide technical assistance to advance state NBS programs.
- X-Linked Adrenoleukodystrophy (ALD): A final evidence review on NBS for ALD was conducted. The council did vote to add ALD to the Recommended Uniform Screening Panel.
- Updates of RUSP implementations: Jelili Ojudo, MPH, and Marci Sontag, PhD, from NewSTEPS gave updates on conditions recently added to the RUSP (SCID, CCHD, Pompe Disease) and the challenges in their implementation. Public health impact assessments have been completed on MPS-1 and X-ALD to evaluate the impact of the addition of conditions to the RUSP.

Presentations and audio recordings of the August meeting are now posted on the [HRSA website](#).

CA Co-Chair Announcement

MSGRC is pleased to announce Yolanda Sandoval as our new CA Co-Chair. Yolanda has continued to provide expertise as a consumer member and her insight on reaching diverse communities, such as the Navajo Nations. We know Yolanda and Lori Wise, our continuing Co-Chair will be active in our plans for Consumer Focus Groups in 2016. We also want to thank Joe Martinec for his outstanding term as CA Co-Chair.

Final Thoughts

As Fall quickly approaches, MSGRC will be working with the National Coordinating Center (NCC) and the other regional genetics collaboratives to lay the groundwork for future years. We want to engage all members in this work and encourage feedback and suggestions. We hope everyone has the opportunity to enjoy these last Summer days!

Warm regards,



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