



Message from the Project Directors Celia I. Kaye, MD, PhD & Kathryn Hassell, MD

Join Our List.

[Join Our Mailing List!](#)

April 2015

Greetings,

April has given many of our states both sunny days and much needed rain. Fortunately for MSGRC, the weather this last week in Phoenix was perfect for our Annual Meeting. Warm weather and mountain views were much enjoyed by many attendees who spent evenings in the courtyard catching up with dear friends and colleagues as well as making new connections.

Highlights from the MSGRC Annual Meeting

Jan Lowery, University of Colorado, delivered her keynote presentation, "The Dream Stream," focused on access to cancer genetic services. Dr. Lowery's presentation was notable and timely as access to genetic services will be of key interest to MSGRC in the upcoming grant year. We also welcomed Dr. Nathan Slotnick, who was able to provide insight as a practicing Medical Geneticist on the future of medical genetics and what a needs assessment might target. Dr. David Flannery's presentation and open discussion on "NCC Today and in the Future" asked for feedback from attendees on how genetic services should be defined and the role of public health in genetic services. The survey from the NCC can be completed [here](#). Attendees were also especially excited to hear from Joan Scott, Chief of the Genetic Services Branch, and Joe Bocchini, Chair of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC). Al Romeo (OTIS), Sharon Romelczyk (Genetic Alliance), Gina Pola-Money

(LEND), and Marci Sontag (NewSTEPs) also gave outstanding presentations.

In addition to the keynote and national speaker session, Parent Partners also hosted a panel that discussed their experiences with this project. Our special thanks to Brad Thompson, Dr. Cathy White, Karla Ahlbourn, and Susan Peterson for providing updates and personal insight on what has been one of MSGRC's most active and successful projects over the last two years.

All six workgroups (Newborn Screening, Telegenetics, Health Information Technology, Medical Home, Consumer Advocacy, Emergency Preparedness) also had very productive meetings. Work was done on many ongoing projects and planning for the next grant year was also conducted. Notable items included NBS timeliness and the addition of disorders to the Recommended Uniform Screening Panel (RUSP), discussion on the EP survey Results, Project Echo (a model that uses video teleconferencing for case-based training), NBS education for families, and Family History Tools. The Hemoglobinopathies and Metabolic Consortium also met again. State updates, long term follow-up, and care plans were some of the topics discussed during these meetings. The MSGRC Annual Meeting was productive for all and the work accomplished in Phoenix will be fundamental in next grant year's activities.



Kathy Hassell delivering the "State of the Region Address"

A Special Thanks

MSGRC would like to thank our Annual Meeting Sponsors below. The sponsor booths were visited and enjoyed by many attendees and we hope our sponsors will join us again next year!

Platinum Sponsor: **PerkinElmer**

Gold Sponsors: **Hyperion Therapeutics** and **Oz Systems**

Silver Sponsors: **Oxford Gene Technology** and **Prevention Genetics**

Other Items

Shodair Children's Hospital in Helena, Montana is currently looking for a full-time dietitian. Please follow the [link](#) to find more information on this opening.

The American Academy of Pediatrics (AAP) will be hosting a 60 minute webinar titled Heritable Diseases in the Navajo: Fallout from the American Indian Wars of the 19th Century. More information on this free 60 minute webinar can be found [here](#).

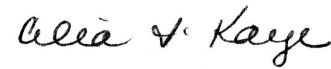
If you haven't already done so, please take the Working Together Survey. Your input is valuable as MSGRC looks to continue and improve collaboration in the region. The survey can be accessed [here](#).

Closing Thoughts

It was a true pleasure seeing everyone in Phoenix this last week. We saw many new faces in addition to some of our old friends. Photos from the meeting are now on our [Facebook page](#) and **presentations are available [here](#)**.

Next month, Celia Kaye will step down as Project Director and Kathy Hassell, current Associate Project Director, will fill this position. Our new grant year will bring many changes, many of which we are excited to embark on.

Warm regards,



Celia I. Kaye, M.D., Ph.D.
Project Director



Kathryn Hassell, M.D.
Associate Project Director

MSGRC staff contact information:

Celia Kaye, Project Director
Celia.Kaye@ucdenver.edu

Kathryn Hassell, Associate Project Director
Kathryn.Hassell@ucdenver.edu

Joyce Hooker, Director of Regional Outreach
jhooker@msggcc.org 303-978-0125

Marilyn Brown, Project Manager
mbrown@mountainstatesgenetics.org 512-279-3919

Kristi Wees, Social Media Coordinator
kwees@mountainstatesgenetics.org

Website: www.MountainStatesGenetics.org

Acknowledgement

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under Grant H46MC24095. The Mountain States Genetics Regional Collaborative for \$600,000. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

[Forward email](#)

 [SafeUnsubscribe](#)

This email was sent to kwees@mountainstatesgenetics.org by mbrown@mountainstatesgenetics.org | [Update Profile/Email Address](#) | Rapid removal with [SafeUnsubscribe](#)™ | [Privacy Policy](#).



Mountain States Genetics Regional Collaborative | 8501 North MoPac Expressway | Suite 170 | Austin | TX | 78759