



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

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**June 2017**

Greetings,

You may be asking why the monthly PD message is off to such a celebratory start, balloons included. We are extremely excited to welcome all of our members, partners, and colleagues to our new funding cycle as the Mountain States Regional Genetics Network (MSRGN)! Funding from the Health Resources and Services Administration (HRSA) for the three-year cycle as the MSRGN will go from June 2017 to May 2020. Please read on to learn more about the mission, structure, and goals of the MSRGN.

### **A Look Inside the MSRGN**

How will the MSRGN differ from the previous cycle as the MSGRC? The MSRGN is evolving from the Mountain States Genetics Regional Collaborative (MSGRC) to a program that will focus on facilitating access to genetic services for underserved populations. In our region, we have identified (with the input of our membership) the main barriers to include rural locality, racial and ethnic inequities, and financial barriers. To successfully facilitate access to services, the MSRGN will function as a network of partnerships and connections that link state health department leaders, providers (genetics or primary care

pediatrics), community organizations and consumers. MSRGN will work with each state to develop a state team that has representation from the diverse stakeholders that will be served by our network. This model was developed from the outcomes of MSGRC's needs assessment and strategic planning meetings over the last two years. The consensus was that the eight states in our region have diverse landscapes, with distinct underserved populations, health department resources, and clinician (primary and genetics) supply.

State teams will be convening over the next several months to pull together information on the underserved in their state and the key organizations and partners that serve or could serve them. Consumers were vital to MSGRC and will continue to be central to the future activities of the network. Consumers will serve as key members on both our state teams, workgroups, and projects. While the MSRGN will be initially contacting individuals to assist with organizing the state teams, please contact us if you are interested in becoming a key member on a state team.

To fulfill the mission outlined above, the MSRGN has identified four central goals:

**Program Goal 1: Link medically underserved populations to genetic services.**

**Strategies:**

- Establish state-based teams with representation from key stakeholders including providers, healthcare systems, public health, and consumers.
- Initial engagement to include clinics in Texas, Colorado, and Montana where significant underserved populations have been identified.
- Establish a relationship with Indian Health Services in Arizona and New Mexico.
- Social media campaign to increase awareness of MSRGN and establish interactive website.

**Program Goal 2: Implement quality improvement (QI) activities to increase the connection with genetic services for the medically underserved.**

**Strategies:**

- Establish a MSRGN QI team
- Participate in National Coordinating Center(NCC) in-person and virtual QI training activities.
- Participate in identified national QI projects as determined by the NCC.
- Provide technical assistance for QI activities for projects conducted within MSRGN.

**Program Goal 3: Implement evidence-based innovative models of telehealth and/or telemedicine with a focus on clinical genetics outreach.**

**Strategies:**

- In collaboration with the Telehealth Resource Centers within the region, offer training for providers at the annual Genetics Summit.
- Facilitate MSRGN member participation in telegenetics training in Heartland RGN (physicians) and Western States RGN (genetic counselors).

**Program Goal 4: Provide resources to genetic service providers, public health officials, and families.**

**Strategies:**

- Expand MSRGN website to become interactive and warehouse educational materials, tools, and links to other resources to be used by providers, consumers, and public health professionals.
- Use state-based teams to link resources from all key sectors within each state to facilitate awareness of programs available to individuals and families.
- Hold annual Genetics Summit with broad attendee representation.
- Partner with state AAP and AAFP chapters to disseminate educational materials and newsletters to primary care providers.
- Identify new primary care network partners and promote use of the Medical Home Portal.
- Work closely with NCC and National Genetics Education and Family Resource Center to develop new educational materials and promote family/consumer engagement.

Through the availability of technical assistance, educational outreach, and innovative models of telehealth, the MSRGN will focus on increasing the number of individuals receiving genetic and support services. The MSRGN's initial efforts will be focused on outreach to rural, Hispanic, and American Indian populations, all of whom face additional geographical and cultural barriers to service from primarily urban genetic centers.

The MSRGN would like to again thank our membership for their engagement in needs assessment, strategic planning, and the grant application process. It is through a diverse membership we have been able to develop a

comprehensive approach as the MSRGN to link the underserved to genetic services. While ambitious, we know it will be achievable through the network of partners that the MSRGN will engage.

### **"Working Together" Survey**

We would like to remind all of our members and partners that the ["Working Together" survey](#) is still available to complete online. We hope to hear your thoughts and inputs on our past work as the MSGRC. This will be particularly informative as we move into a new cycle as the MSRGN. We are actively strategizing how we can provide opportunities for engagement and improve communication across our region as we initiate groundwork on a new three-year cycle.

### **NBSTRN Meeting**

Janet, Kathy, and Marilyn recently attended the NBSTRN meeting in Washington, DC, from June 1-2. It was a packed [agenda](#) with topics ranging from genomic sequencing in infants in the NICU, updates on state newborn screening pilot projects, and ethical issues around newborn screening. Please follow the linked [agenda](#) to review all the topics discussed. Meeting slides will be made available in the near future through the NBSTRN site. In the meantime, visit the NBSTRN at their [Facebook page](#) to see photos from the meeting. Don't forget to Facebook "like" the NBSTRN while visiting!

### **Webinar Opportunity**

MSRGN would like all of our partners to be aware of a webinar opportunity on June 15 from 11-11:30 am MT, "A New Tool to Measure Family Experience of Care Integration to Improve Care Delivery," sponsored by the Lucile Packard Foundation for Children's Health, the Catalyst Center, and Family Voices.

The webinar will cover the Pediatric Integrated Care Survey (PICS), a validated instrument from Boston Children's Hospital created to assess the family experience of care integration. The survey that has been created asks family respondents to identify their child's/youth's care team and report on their experiences with care integration. Those interested in attending can register [here!](#)

**#Race4Respect**

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The Devenio, Inc., an organization focused on helping individuals with Down syndrome and other developmental disabilities held a 5k last Saturday in downtown Washington, DC. Devenio focuses on building partnerships to create life-long opportunities for this community and increase education and awareness. Marilyn was happy to be there at the start line in support of what was a well attended event. Sean McElwee, from the Emmy awarded show *Born This Way*, was even in attendance. Learn more about Devenio, Inc on their [website](#) and follow their Facebook link to check out photos from the 5k!

### Closing Thoughts

As the MSRGN initiates new work, please be on the lookout for updates over the next month! We currently have many projects in progress, such as a website re-design that will reflect the new work of the network and be more interactive for our members and stakeholders. As always, please do not hesitate to reach out to us with any thoughts. Your input is vital as we quickly move into our new scope of work.

Warm regards,



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