



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

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July 2017

Greetings,

Last month, we were happy to introduce the new Mountain States Regional Genetics Network (MSRGN). Since then, we've been quickly laying the groundwork for our proposal for the three-year cycle. Strong member and partner participation will be at the forefront of the MSRGN. Please continue on to learn more about what activities are in progress and opportunities to become involved.

The Underserved Populations Project (UPP)

The overall role of the MSRGN will be to facilitate access to genetic services for underserved populations in our region. To work towards this mission, we have quickly initiated work that will allow us to begin efforts to increase access to underserved populations in our first year. We know from our meetings and focus groups, in which many of you participated over the years, there has been a great need to better target the unique barriers limiting access to health care and genetic services for American Indian, Hispanic, and rural. With this in mind, we initiated the Underserved Populations Project (UPP). The final objective of this project is to develop tailored approaches to sites that have been identified as initial "target sites," in which the MSRGN will increase access to genetic services in year one of our three-year funding cycle.

As part of this project, we have engaged consumer members to give input in the design of this project, including the development of a series of questions to interview consumers/patients on elements related to genetic and health care service access. In addition to this activity, we are planning on recruiting consumers that represent our target communities to respond to our consumer questionnaire. This will be of high importance in our end goal of creating solutions for both families and genetics

clinics that improve the access to care for the diverse populations in our region. Our first project call with our consumers is planned for August 2. If interested in becoming involved on our consumer project workgroup, please contact Marilyn Brown.

State Team Planning

June's message discussed the formation of state teams that will consist of 3-4 individuals in each of our states, with individuals representing state health departments (NBS, Title V, Medicaid), genetics and primary care providers, community support groups, and families. MSRGN seeks to begin to understand and broker communication between work with and facilitate communication between these entities. The long-term goal is to form a state-based genetics network in each state that can better serve families and participate in region-wide projects.

The first call has been planned for August 2. The MSRGN has already identified key individuals across our region but is still actively recruiting for the state teams. We welcome nominations from all of our states.

July Announcements

- As a reminder, the next ACHDNC meeting will be held August 3-4. Registration will be open soon and can be completed at <http://www.achdncmeetings.org/>.
- The MSRGN will be launching our new website in August. As part of this process, we are looking for feedback on usability and content of the newly designed site. Please contact Marilyn if you are willing to give us your feedback and input on the new site!

Closing Thoughts

We would like to give our thanks to our members that have given their input and volunteered for current MSRGN activities. As always, we pride ourselves on being an open forum where all members have equal voice. Do not hesitate to reach out if you would like to lend your voice as we set the foundation for our region's future!

Warm regards,



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