



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

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October 2017

Dear friends and colleagues,

There are several upcoming opportunities and meetings we would like our members to be aware of this month. We hope to see many of our members and colleagues in attendance.

Consumer Advocacy Training Opportunity

MSRGN would like all of our members to be aware of the upcoming training series offered through our partner in consumer advocacy and resources, Family Voices. "Serving on Groups," is targeted for families that serve or would like to serve on decision-making groups will be held on November 15, 2017. "Leading by Convening" is focused specifically for leaders of groups, such as Title V Directors. More information, including the Family Voices media announcement, can be found [here](#).

We are pleased to be able to sponsor the costs of attendance for up to three consumers for our region. Please follow the link above to learn more information regarding this opportunity.

Upcoming ACHDNC Meeting

The next Advisory Committee on Heritable Disorders and Newborn Screening (ACHDNC) meeting will be held in-person November 8-9, 2017 in Rockville, MD. The meeting will also be held via webcast for those attending remotely.

Agenda items include:

- updated from states on newborn screening timeliness goals;

- presentation on Phase II of the spinal muscular atrophy evidence review;
- presentations on newborn screening topics (clinical and public health impact of SCID, carrier status in the context of NBS, review of long-term follow-up in NBS);
- and updates from workgroups (Laboratory Standards and Procedures, Follow-up and Treatment, Education and Training).

Registration will be open until November 6 for those interested in attending in-person or via webinar at <http://www.achdncmeetings.org/>. The full meeting announcement can be accessed [here](#).

Regional Updates

- MSRGN continues to make progress on our Underserved Patient Populations Project (UPP). With input from our clinic sites, we are now working at our sites to implement interventions to increase access.
- MSRGN has welcomed several new members to our Steering Committee.
- For our state health department partners, please visit our [State Team pages](#) on our website. Over the next couple months, we will be working to populate these pages further. We welcome feedback!

Changing Leaves

This time of year is a personal favorite of ours, when leaves begin to change and holidays bring family and friends together. This month, we're looking forward to pumpkin patches, trick or treating, and apple cider. We hope all of you have a wonderful October!

Warm regards,



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