



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

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November/December 2012

Greetings!

This is a bittersweet season this year, as we celebrate the winter holidays in the midst of tragic events in Newtown, CT. As an organization dedicated to the well-being of children and their families, we can reach out to those we know around the country who are impacted by this tragedy. We can also work in our own communities to take steps to ensure the safety of all children and teachers in our schools and neighborhoods. The American Academy of Pediatrics has resources available for parents, students, and schools. You can find more information [here](#) resources to website.

MSGRC 2012-2013 Annual Meeting

Registration for the MSGRC 2012-2013 Annual Meeting is now open! You can find out more about the meeting, view the draft agenda, and link to registration by visiting our website at http://www.msgrcc.org/events/midyear_meeting_march13.html.

MSGRC Project Highlight

Earlier this year, MSGRC received supplemental funding through HRSA to develop a strategic plan for expanding use of family history tools in our region. Family history can help providers determine an individual's risk for certain diseases, both common (e.g. congenital heart disease) and rare (e.g. Fragile X). Family history tools offer providers and families increased knowledge about the possibility that a condition may be passed from affected or carrier parents to a child. Although family history has limitations, the information ascertained from its use helps providers and families make informed decisions about subsequent genetic testing and preventive actions/interventions that may delay the onset of symptoms or reduce disease severity.

The MSGRC project focuses on developing a strategic plan for regional implementation of existing prenatal and pediatric family history tools, including those developed, under development, or supported by:

- The National Coalition for Health Professional Education in Genetics (NCHPEG),
- Genetic Alliance (GA), and
- The Genetics in Primary Care Institute (GPCI).

MSGRC is collaborating with these organizations and other Regional Collaboratives on the project. Throughout the strategic planning process, we will also explore opportunities and barriers to integrate family history tools into the electronic medical record. To develop the Mountain States family history strategic plan we will:

1. Conduct key informant interviews with obstetricians, pediatric primary care providers, and electronic health record vendors to gather information on current use of family history tools, potential barriers to using electronic family history tools, potential barriers to integrating existing tools into the electronic health record, and opportunities for outreach to other providers.
2. Administer a regional survey targeting obstetric and pediatric providers to assess current knowledge about family history and its use in a clinical setting, awareness of existing family history tools, willingness to use new family history tools, ability to integrate tools into electronic health records, and potential barriers to implementing within the clinical setting.
3. Conduct a focus group session to collect information on opportunities for and barriers to region-wide implementation of family history tools in the Mountain States, and to identify existing financial and non-financial resources in the Mountain States that could assist with implementation.

The final strategic plan will summarize:

- The regional goal of improving use of family history tools by obstetric and pediatric primary care providers,
- Opportunities for region-wide implementation of family history tools in the Mountain States,
- The identified barriers to region-wide implementation,
- Existing partnerships that will strengthen implementation,
- A proposed implementation plan accounting for the identified opportunities and barriers, and
- The estimated cost of implementation.

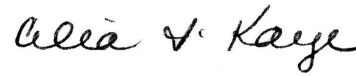
If you have expertise in family history tools and would like to get involved with this project, please contact Liza Creel, MSGRC

Project Manager, at lcreel@mountainstatesgenetics.org.

Closing Thoughts

And so, as the days grow shorter and the nights colder, we will be thinking of you as you gather with family and friends to rejoice in each other and celebrate the season. Thank-you for all you have done for MSGRC and the children and families we serve. We're looking forward to seeing you and hearing your news in the New Year.

Warm regards,



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