

NEGC Update January, 2009

Friends and Colleagues: Happy mid-winter! We are at that pivotal point here in New England where we wonder, “why do I do live here again?”. The shoveling, the scraping, the missed school, frigid cold mornings stumbling around the block and wondering why you’d own a pet that needs walking, and begging children to wear hats and gloves in spite of winter gear being very un-cool, so to speak. But really, if we couldn’t complain about the weather, we just wouldn’t be happy in that cranky, quintessential Yankee sort of way. So, I dug myself out of this weeks storm and thought I’d take the first few minutes of the day letting you know what’s happening here at the NEGC. While I generally write to you once a quarter or so, I thought getting in touch a little more often might be in order—and maybe shorter!

We are spending our considerable amount of time indoors behind the computer screen and getting ready for a number of big upcoming deadlines. The year 3 continuation application is due to HRSA on March 9th, and the writing, brainstorming and number crunching is well under way. While our overall goals and objectives remain the same—improving access to newborn screening and genetic services and the quality of those services, we would like to develop even more creative ways to shape the important work of the NEGC and its constituents. And, while HRSA hasn’t officially released the word, we will most likely have a small budget reduction again this year.

Every time I write the continuation, I reflect on the good and important work you all do. As always, we want to make certain all of your ideas and efforts are reflected in our application so that we represent our region and shine light on its considerable capabilities. Whether you serve on our Advisory Council, the Collaborative Council, are a member of a working group, or you just put up with my questions about your program—very patiently I might add—you are an essential part of our work. This is all to say, I’ll be calling! We have exciting new projects in Education, Medical Home, Transition and Quality Improvement—and those are just the ones on my mind because I am reading their work plans! If you haven’t had a chance, please read the summary of our annual meeting, which gives you a nice idea of what we have done, and what we intend to tackle next year:

http://www.negenetics.org/ongoing_pdf/2008_annual_mtg_summary.pdf

A few more items of interest:

- I would like to thank Ellie Mulcahy and Marcia Lavochkin for agreeing to serve on the National Newborn Screening and Genetic Resources Center (NNSGRC) newborn screening committee. Ellie will serve as the primary representative and Marcia will be her “shadow”, reviewing minutes and stepping in when Ellie has other commitments. We are fortunate to have such capable and experienced representation on the NNSGRC committee.
- The National Coordinating Center has retained a PR and marketing consultant, Kathy Beal. Kathy will work with the regional collaboratives (RCCs) to assess the current marketing and PR resources within the regions, and opportunities for collaboration which will result in maximizing available resources in this area. The value of marketing and communication in our field cannot be over-emphasized and I look forward to working with Kathy. This may be one area where again, I ask you for ideas and projects which are good candidates for broader, national publicity.
- For those of you who haven’t received the many emails or heard the buzz, the Surgeon General released a web-based version of the family health history screening tool, <http://www.hhs.gov/familyhistory/> I tried this out, and it’s pretty impressive. And, a good reminder to me that my somewhat compulsive dedication to exercise is well-founded; heart attacks—including a grandfather who died of a massive cardiac event before the age of 60—are on the tree!

- We are trying to make the NEGC calendar more filled out and are adding events all the time. We'd love to feature your meeting, seminar, webinar or upcoming conference. Please email Karen Smith: karen.smith@unh.edu and she'll add it in. We encourage you to check out our events and attend if you can, or at least know about them so you can download subsequent minutes and summaries.

I look forward to the start of another great year with the NEGC. If you have questions, concerns or comments drop me an email.

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