

## NEGC Update September, 2008

Friends and Colleagues:

Happy Autumn! We have moved directly from buckets of rain to a full two weeks of scorching sunshine to sweater weather—must be New England! Summer is coming to a close—ok, I guess it's time to admit it's actually over altogether. It's the time of year when no matter how long you have been out of school you feel like it's time to pick up a fresh note pad and pen and get down to work. That's just what we've been doing here at the New England Genetics Collaborative and I wanted to send out a brief overview of our recent activities. As always, I would like to thank Karen Smith, NEGC program coordinator, for her patience under scheduling madness, her hard work and her ever pleasant presence. If you haven't had the pleasure of meeting Karen, please drop her an email or introduce yourself when you call the NEGC office.

- Housekeeping first: We submitted the cooperative agreement continuation application to HRSA and were awarded funding for year 2. However, as for all regional cooperatives, HRSA did require a budget reduction of roughly 2%, which was submitted and approved. Our annual performance report was submitted on-line, on time and as required to HRSA this month.
- NEGC has participated in a number of National Coordinating Center meetings and conference calls. There is a real impetus to have the all regional collaboratives from across the country work together to share and develop best practices in the field of genetics and public health policy. We have also been polled to determine what the expertise is around our regions. We have some ideas, but I bet there is lots of untapped potential out there! If you or your organization has expertise you'd like us to know more about in the field of genetics, genomics, health policy, community engagement—think big—please send us an email. We know New England is rich with intellectual resources and it would be great to showcase that at the national level.
- The NEGC annual meeting will be held Thursday, December 4<sup>th</sup> in Portsmouth, New Hampshire. The meeting kicks off with a working session of the NEGC Advisory Committee and Collaborative Council, with the early afternoon dedicated to a national overview and review of NEGC activities for 2008-2009. We are excited to introduce, for the first time, a combined session of the NEGC and the NERGG starting at 3:00: "Incorporating Genetics into the Medical Home ". This opening collaborative session will address this issues regarding coordinated care for children and families with genetic disorders and cutting edge programs in the field designed to promote family centered planning and enhance the coordination of care for this population. Practicing physicians in the field, and families will have an opportunity to address the audience.
- As announced earlier, the NEGC awarded funding for 5 projects under the NEGC Innovative Small Projects program. We had a wide range of highly competitive applications, and were pleased with the mix of consumer-based initiatives, policy and training projects and clinical research proposals. This year, we further enhanced and refined our review process. We were fortunate to have reviewers from around New England and across the United States, representing a wide range of professional expertise. We reviewed entirely on-line, and received positive feedback that the review process was seamless and made it easy to contribute to the group. Our next application cycle is planned for July 2009. Please check our website for a list of funded projects, and summaries of the grants awarded in our first year. In addition, the Innovative Small Grant program awardees will be presenting their projects at a poster session at the NEGC annual meeting on December 4<sup>th</sup>, 2008.
- The NEGC website has been continuously updated, revised and enhanced. Check out our new calendar feature and learn what is going on across the work groups and the region: [www.negenetics.org](http://www.negenetics.org). If you have an item for our calendar, please forward it to Karen—we'd be

happy to add it and keep our membership informed of relevant and interesting opportunities: [karen.smith@unh.edu](mailto:karen.smith@unh.edu). In addition, we are using the website to post materials for working groups and communicate with the groups about meetings. This is our attempt to streamline paper and avoid sending members emails with multiple cumbersome attachments! The password protected areas allow us to post documents which the attendee review at his or her own leisure, printing only when necessary.

- The working groups of the NEGC have been busy. The Medical Home group had a very successful kick off meeting in June and plans to work closely with the Transition working group to develop a pilot project. The Dissemination, Education and Marketing work group will focus this year on special educators working with children who have genetic conditions. They plan to release a survey to determine what these professionals would most need to assist them as they work with these children in the classroom setting. The Quality Improvement working group has now focused on moving into phased electronic database collection, which will ultimately result in a multi-site registry with full EMR integration. The QA Working Group has initiated a project to obtain objective evidence about the applicability of the New England Newborn Screening Program (NENSP) algorithms to other NBS laboratories in Region 1 and across the country. The Long Term Follow up Working Group continues to meet and refine the data collection efforts across several disease categories. This is just a brief summary, there are many exciting projects underway! For more details, an end of the year report outlining all the NEGC activities has been finalized and will be posted on the NEGC website shortly.
- The NEGC evaluation staff also conducted a stakeholder survey, gathering feedback and ideas from our constituency. In general, we received high marks and performed well. As always, we want to make sure we are communicating all that we do and working to ensure everyone feels included. If you have ideas or suggestions about this for the NEGC, I would welcome them: [amy.schwartz@unh.edu](mailto:amy.schwartz@unh.edu). And of course, we encourage you to participate in next year's survey. We do this on line and try to make it as painless as possible, we promise! We want getting in touch and telling us how we are doing to be nearly effortless.
- Publish, publish, publish! We want everyone to know about the good work we do. As such, we'd like to foster research and writing collaborative efforts with our partners across the region. In conjunction with the UNH School of Health Management and Policy, the NEGC submitted an abstract that was preliminarily accepted to a special supplement to Pediatrics. Using the national Children with Special Health Needs survey, we are analyzing the barriers to receiving genetic counseling for the families of children with Down Syndrome, Autism and Intellectual Disability. Following my attendance at the national Pediatric Bioethics conference in July, the NEGC has also initiated draft white papers in the field of ethical, legal and social issues. We are continuously seeking opportunities to write together and advance the knowledge of policy and genetics in the field of public health. If you have an idea and think we can help, send along an email. It may not happen tomorrow—we are all busy—but we'd like to get some ideas in the hopper!

Thank you again for your time and interest. We look forward to hearing from you.

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