



Dear NEGC partners,

I am writing at this time to update all of you on the activities of the NEGC to address our shared work to improve access to and the quality of genetic services in New England.

To accomplish this important work, we are fortunate in having colleagues such as you working together to further the NEGC mission.

Annual meeting

NEGC had a very successful two day meeting in December in which 46 individuals participated. Five of the work groups met, which offered opportunities to document successes to date and plans for the future. Sara Copeland, HRSA, and Judith Benkendorf, NCC, provided a national perspective. The Advisory Committee also met and welcomed two new members. A summary report will be coming soon.

Community and Family Network Grants

New this year are “Community and Family Network Grants” designed to encourage the development of small community-based projects that address the needs of people with genetic conditions.

Go to http://negenetics.org/Community_grant/Community_grant.html

We have funded four applications to family support organization members to attend leadership development conferences.

Providing training opportunities

NEGC is a co-sponsor with the Genetic Alliance in sending a lay person from New England who was selected to attend the Genetic Alliance Advocates Partnership Program at the ACMG annual meeting in Albuquerque, NH, later this month.

NEGC is sending seven nutritionists representing every NE state to the Genetic Metabolic Dieticians International (GMDI) Educational Conference in Baltimore, MD, in April. Members of our advisory committee and collaborative council developed selection criteria to help us best meet the needs in the region.

Innovative Project Awards

NEGC is initiating the fourth round of *Innovative Project Awards* this spring. We will notify you when the RFP is released, but you can expect the letter of intent to be due in mid April. Please check our website or contact Karen Smith (Karen.smith@unh.edu) for more

information. This has been a highly successful program and we look forward to another year.

Forging new collaborative partnerships

Building on momentum generated earlier in the region, we are creating a new Learning Collaborative involving leaders from metabolic clinics in New England. The regional planning group for this effort has 3 meetings scheduled this Spring and intends to kick-off the Learning Collaborative next year with invitations sent early summer 2010.

Along with other regional collaborative, NEGC is beginning to work with the Genetic Alliance in their NBS Clearinghouse cooperative agreement with HRSA. This relationship is forming now. See the Clearinghouse website for more information:

www.nbsclearinghouse.org.

Improving Resources and products

The Dissemination, Education and Marketing (DEM) group is moving along on development of web-based tool for educators working with children with genetic conditions. In February they conducted their first focus group regarding the tool at a school in CT, and others are scheduled. *The group is still looking for a school in an urban setting to host a focus group.*

NEGC supported new research efforts; one example: [Potential Impact of Genomic Information on Childhood Sibling Relationships](#).

Systems Change

A new data registry being developed will be shared and accessed by multiple clinics in the region, enabling a better understanding of patient needs, care processes, and needed areas of improvement.

The work of the Quality Assurance group continues to improve accuracy of lab tests as members expand their analysis work to include new markers and their utility in establishing better identification methods for children with genetic conditions.

Regional LTFU initiatives enable better identification and follow-up of children born with genetic conditions in the New England region.

Improving our communication strategy

NEGC continues to focus on improving outreach to both consumer and professional groups. We have plans to update our website and enlist the help of Kathy Beal, Director of Public Relations with ACMG.

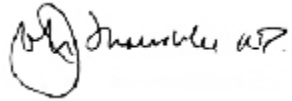
If that's not enough...

NEGC is working to complete multiple special projects, including Genetic Workforce study, Medical Home and Transition Pilot Study, Assessment of Transition Practices in the Region, Legal Analysis of Cross State Data Sharing, and Multiple Fact Sheets for Parents on Genetic Disorders.

We are heading into a busy spring with many of us attending the annual meetings of ACMG and SIMD.

It is important to take the time to congratulate you on the good work you all do. Collaborate does mean "to labor together" and indeed this is what we do.

Warmest Regards,

A handwritten signature in black ink, appearing to read "John B. Moeschler". The signature is written in a cursive style with a large initial "J" and "M".

John B. Moeschler
NEGC Project Director