

## **NEW ENGLAND GENETICS COLLABORATIVE**

### **Summary of Year Four Project Activities and Accomplishments**

The current New England Regional Genetics and Newborn Screening Collaborative (NEGC) grant (HRSA Grant # U22MC10980) officially began June 1, 2007. In reviewing the goals and objectives for Year Four (June 1, 2010 through May 31, 2011), 96% of 54 objectives have either been completed (63%) or have made satisfactory progress (33%) in accordance with the long term goals of the grant. Concerning stakeholder satisfaction with the progress of the NEGC, findings from the recently completed stakeholder survey showed multiple improvements over the previous year. A majority of respondents (N=63) understood the mission of the NEGC (73%) and felt that the NEGC has made clear and substantive progress in achieving its mission (72%).

During its fourth year of activity, core project staff have continued to focus on improving the infrastructure of the NEGC (launching the new website, improving the guidelines and review process for the Innovative Project awards, adding an advocacy committee, supporting partner organization grant applications) and increasing support to stakeholders. Together with the work groups, project staff have been meeting and carrying out the work of the NEGC through a broad range of activities, including a special focus on metabolic centers workforce capacity and launching New England's first Emergency Preparedness symposium. Additional work group highlights include:

- The Quality Improvement work group implemented a registry accessed by a web-portal to collect data on care processes for patients referred for global developmental delays and/or intellectual disabilities. The workgroup successfully launched a new learning collaborative with 8 participating metabolic centers representing all NE states.
- The Transition work group continued to build on both regional and national level activities, implementing a new Teen Challenge Program, disseminating the Transition Toolkit, and collaborating with national partners.
- The Medical Home work group pursued the development of a new survey needs assessment to document care, coordination and communication practices among primary care providers, specialists, and families.
- The Dissemination, Education, and Marketing work group developed the framework and background material for the new GEMSS website for special educators to improve support for students with genetic conditions ([www.gemssforschools.org](http://www.gemssforschools.org)).
- The Laboratory Quality Assurance work group conducted analyses and compared results to follow-up for: 3MCC, BKT, GA-I, MSUD, CIT-I, and ASA, with a presentation to the Laboratory Subcommittee of the SACHDNC.
- Lastly, the Long-Term Follow-up work group achieved a major accomplishment by solidifying an agreement with legal representatives from Rhode Island that allows for the collection of LTFU data. Additionally, they held a national conference on improvement of long-term outcomes for individuals with Sickle Cell Disease.

For more details on the work of the NEGC, the reader is encouraged to review the full evaluation report online at [http://www.negenetics.org/AboutUs/Evaluation\\_reports.aspx](http://www.negenetics.org/AboutUs/Evaluation_reports.aspx). Questions concerning the project's evaluation should be directed to Peter Antal, Ph.D., NEGC Project Evaluator, at [Peter.Antal@unh.edu](mailto:Peter.Antal@unh.edu).