

**New England Genetics Collaborative**  
**Annual Evaluation Report for Year 2**

**Reflections on Project Activities 6/1/08- 5/31/09**

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# New England Genetics Collaborative

## Annual Evaluation Report for Year 2

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## EXECUTIVE SUMMARY

This annual report covers the activities of the New England Genetics Collaborative (NEGC) from June 1, 2008 to May 31, 2009. The purpose of this report is to provide the reader with additional documentation on the utilization of grant funds and what has been achieved as a result, provide an overview of NEGC activities for both old and new partners, and to offer recommendations for the Collaborative's improvement and ultimate achievement of its mission and vision.

*Mission: The mission of the NEGC is to promote and improve health and social well-being of those with inherited conditions through collaborations among public health professionals, private health professionals, educators, consumers and advocates in ME (ME), New Hampshire (NH), Vermont (VT), Massachusetts (MA), Rhode Island (RI) and Connecticut (CT).*

*Vision: All individuals with genetic conditions living in New England have the opportunity to achieve their fullest potential.*

This report includes a summary of activities by the Regional Coordinating Council (RCC), Working Groups, and Evaluation staff during the period, primary findings of the project's second stakeholder survey, an update on the status of core project components from Year Two, a list of objectives for each group for Year Three, and recommendations to the project by evaluation staff. The material provided in this report is based on materials submitted to evaluation staff by project staff as of Oct. 1, 2009. Members of the Collaborative Council were provided an opportunity to review and comment on the enclosed material. Evaluation of the project is led by Peter Antal, Ph.D., Institute on Disability, UNH.

The current New England Regional Genetics and Newborn Screening Collaborative (NEGC) cooperative agreement (HRSA Grant # 2 U22MC10980) officially began June 1, 2007. During its second year of activity, core project staff have continued to focus on improvement of the infrastructure of the NEGC and increasing support to coalition members, and, combined with the Working Groups have been meeting and carrying out the work of the NEGC. The Quality Improvement Working Group has continued to refine its work around a genetics registry and developing common quality measures across major clinics. The Transitions Working Group has continued to build on both regional and national level activities, including several events to help youth with genetic conditions successfully transition to adulthood. The Dissemination, Education, and Marketing Working Group has focused on providing special educators with comprehensive and easy to access information that will help classroom staff provide a more inclusive environment for children with genetic disorders. The Medical Home Workgroup has outlined a pilot study for creating a more effective referral process that will involve family members, patients, clinic specialists, and primary care providers. The Laboratory Quality Assurance Working Group has continued to expand on its work assessing C3 elevations and learning how to fine tune their analytic approach across different laboratories. Lastly, the Long-Term Follow-up Working Group has continued to educate both regional and national stakeholders about the need for developing long term follow up systems and also focused on developing new research around the psychosocial implications of diagnosis as well as creating a psychosocial assessment tool which could be used by non-psychologists.

Concerning stakeholder satisfaction with the progress of the NEGC, findings from the recently completed on-line stakeholder survey continued to document the spirit of cooperation that is in place, as well as the expertise of those gathered to participate. Following on issues cited in Year 1, there continues to be a need for better understanding of the NEGC's mission and accomplishments. Respondents again provided multiple recommendations on how the project could best move forward in Year 3.

In reviewing the goals and objectives for Year 2, objectives have either been completed or have made satisfactory progress in accordance with the long term goals of the grant. Objectives for Year Three have been shared and agreed to by project staff and chairs of the project's work groups. These objectives will be reviewed by the Advisory Council in preparation for Year Four funding requests. In preparing to successfully meet the collaborative's objectives, the evaluation recommends a series of next steps for the project, including: continued collaboration around grant opportunities, further clarifying the roles of stakeholders in the collaborative, creating additional time for collaboration across groups, further refining performance measures and workgroup reporting, and continuing to support individual workgroup initiatives.

## **COALITION CHANGES AND IMPROVEMENTS**

### **Organizational Overview**

The Regional Coordinating Center (RCC) is staffed by Dr. John Moeschler, who serves as Principle Investigator, Ms. Amy Schwartz as Project Manager, Ms. Karen Smith as Project Coordinator, and Peter Antal, Ph.D. as Project Evaluator. Administrative support is provided by the UNH Institute on Disability, which acts as fiscal agent.

In 2008 – 2009, the RCC carried out substantial portions of its work through six Working Groups: Quality Improvement, Medical Home, Transition, Laboratory Quality Assurance, Long Term Follow-Up, and Dissemination, Education and Marketing. The chair of each Working Group is a member of the Collaborative Council; the Council meets quarterly to facilitate coordination of Working Group activities. The RCC and Collaborative Council are guided by an Advisory Council which meets annually to help set direction for the collaborative and to provide feedback / raise issues throughout the year as needed. Lastly, a review committee is formed annually to provide review and guidance on funding requests from the collaborative's innovative projects program. Please see Appendix A for the current organizational chart.

### **Organizational Improvements**

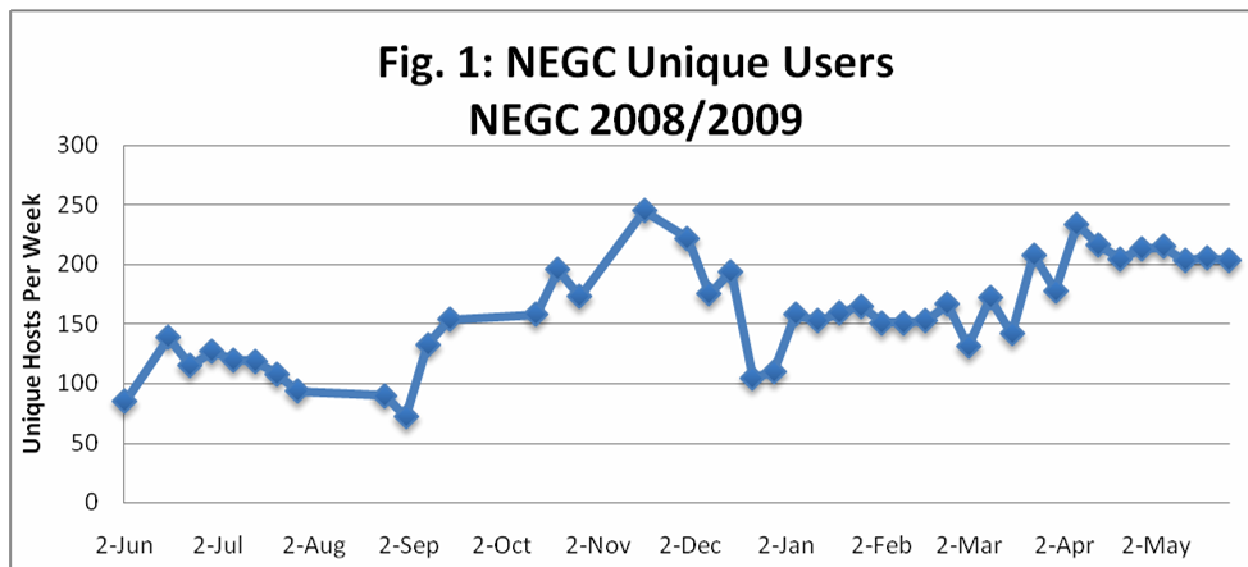
The NEGC staff have continued to focus on enhancing communication among NEGC constituents groups, built the website capacity and functionality, and sought to leverage new grant resources to support achievement of the NEGC's mission.

### **Communication Among Staff and Collaborative Council Members**

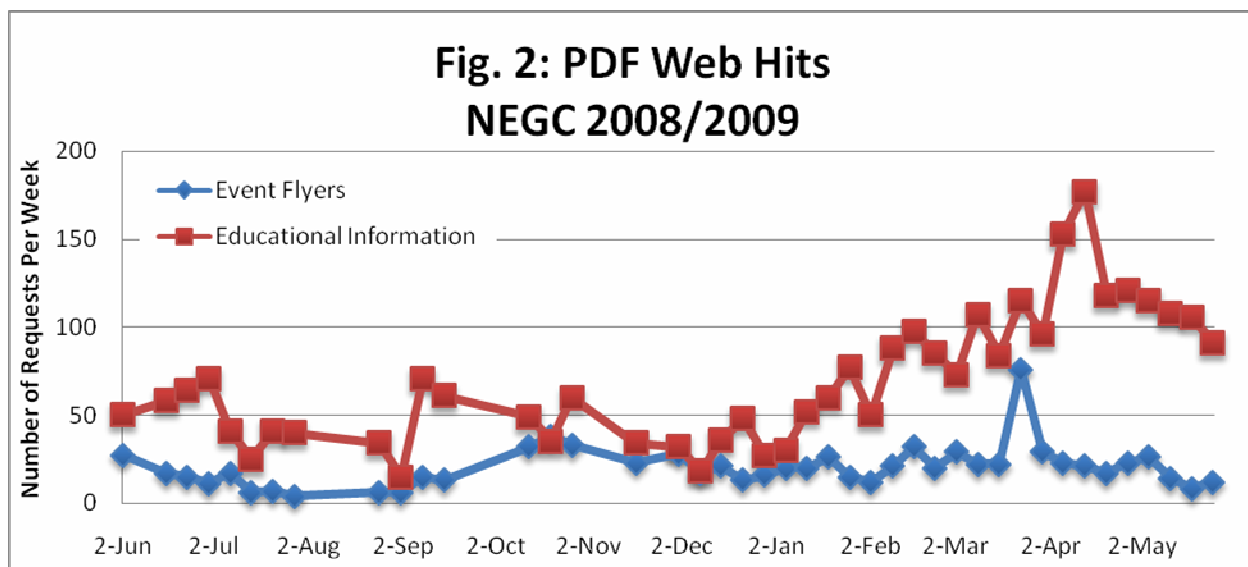
A major change for this year was to add monthly calls between project staff, the project evaluator, and workgroup chairs. This has been a major aid in improving communication among staff and highlighting new opportunities for collaboration across workgroups as well as with new initiatives across the nation. Project staff have also made better use of web-based technologies, such as webinars and virtual meetings, to help address some of the geographic and time barriers experienced by project staff during Year One. Medical Home and Transition monthly calls have been combined in many instances as a direct effort to enhance the inter-relatedness of the groups. This has now evolved for Year Three into a medical home pilot project management team meeting including Dr. Chris Stille, UMass Med, and the project's PI.

### **Website Improvements**

During the course of the project year, project staff made multiple improvements in the design and structure of the website. Primary changes made include: updating member information, adding multiple informational resources, utilizing google's mapping function to post a map of clinical genetic sites across New England, and re-organizing the structure of the website to make it more accessible for working group and advisory council members.



During the year, there was a gradual increase in unique users accessing the NEGC website; from 85 during the week of June 2, 2008 to 203 during the week of May 25, 2009 (See Fig. 1). In terms of information requests, there was a consistent level of requests for information on upcoming events throughout the year while requests for informational resources on genetics issues increased substantially over time (see Fig. 2).



The highest number of requests was during the week of April 13. Resources with 10 more requests during this week included: genetics directory, information from the David Ledbetter webinar, the NCC Collaborator (March and December editions), and the Spanish genetic hearing loss booklet.

### Resource Leveraging

During Year Two, NEGC staff submitted six grant applications to support new or expanded work in the genetics field in the New England region. As of Oct 1, 2009, two applications were funded for \$111,000 to

support enhancements to the QI data registry and assessments of the genetic workforce. Four applications were declined.

Name	Description	Status
Administrative Supplemental	HRSA; funds for QI data registry and electronic medical record pilot	\$75,000 FUNDED April 09
Assess capacity of genetic workforce	ACMG; assess genetic workforce in light of expanded nbs; Bob McGrath will collaborate	\$36,000 FUNDED April 09
Down Syndrome Surveillance	CDC; 4 yr grant for \$400,000 to study prevalence of DS at birth and older ages; overview of health across lifespan; Bob McGrath, David LaFlamme, IOD will collaborate	NOT FUNDED
Genetics Health Care Quality Improvement Project: A Multi-State Pilot Collaboration	AHRQ; \$300,000 for 2 yrs QI activities	NOT FUNDED
Dartmouth Translational Research Center	Submitted by John Moeschler to supplement QI project	NOT FUNDED
Galactosemia and Premature Ovarian Insufficiency	AUCD; collaboration with Susan Waisbren; submitted Oct 08	NOT FUNDED

### Collaborative Activities

Project staff have actively sought new opportunities for partnerships with both regional and national partners. During Year 02, this has included: collaborating with the UNH Institute for Health Policy and Practice on grant preparations, sharing project information with NYMAC, and learning from other regional collaborative efforts. Initial conversations have been held to organize a possible joint funding application between Genetic Alliance, the Heartland Region and the New England RC to address the issue of family health history. Other areas of collaboration include the NEGC annual meeting, presentations to regional and national partners, publications in the field of genetics, supporting innovative projects in the region, and supporting the work of the National Coordinating Council (NCC).

### Annual Meeting, Dec. 4, 2008

The NEGC collaborated with the New England Regional Genetics Group (NERGG) to host a joint annual meeting of the two groups. The NEGC annual meeting was attended by 36 people from all participating

states in the region as well as national groups and represented physicians, state planners, and family members of consumers. Participants had an opportunity to learn about new developments both regionally and nationally, discussed challenges to the project, and suggested improvements for achieving the collaborative's mission.

### **Presentations Supported by the NEGC**

During Project Year 2, NEGC coalition stakeholders provided 21 presentations or poster sessions in the process of either sharing work about project activities (7), educating students (4), or training professionals about best practices in the area of genetics services (10). Of these, several resources have been posted online, including: Family Health History Awareness, Psychosocial Considerations for Transition, and Incorporation of ANA Guidelines on Genetics for Nurse Educators. For a detailed listing of presentations and presenters, please see Appendix B.

By the end of Project Year 2, five additional publications were created by NEGC collaborative council members, bringing the total publications list of NEGC stakeholders up to nine. These most recent publications include:

- ❖ Dr. Anne Comeau
  - *Population-based research within a public health system: two models for common rule compliance in the Massachusetts Newborn Screening Program.* In: Ethics and newborn genetics screening: New technologies, new challenges.
  - *Oropharyngeal flora in healthy infants: observations and implications for cystic fibrosis care.* Journal: Pediatric Pulmonology
- ❖ Dr. Susan Waisbren
  - *Parental tolerance of false-positive newborn screening results.* Journal: Pediatric Adolescent Medicine
  - *Short-chain acyl-CoA dehydrogenase (SCAD) deficiency: an examination of the medical and the neurodevelopmental...* Journal: Molecular Genetic Metabolism
  - *Stability of blood phenylalanine levels and IQ in children with PKU.* Journal: Molecular Genetic Metabolism

For a detailed listing of publications supported by the collaborative and its members, please see Appendix C.

### **Innovative Projects**

The RCC continued to build on the innovative projects program and completed its second round of grant funding. The NEGC received 12 letters of intent to apply in June of 2008 and awarded five grants in September 2008, with a combined total disbursement of \$100,000. The studies funded by these grants include:

1. “*Patient as Teacher Project*,” by Dr. Mark Korson of Tufts-New England Medical Center in Boston, Mass. \$20,000 in funding was provided for supporting patient and family members as well as additional organizations as speakers for the Metabolic Outreach Service. The ultimate goal for this effort was to increase awareness about metabolic disease among clinicians, medical trainees and other health care professionals through an ongoing educational program. More than 50 future speakers, either patients or family members, representing over 20 different metabolic diseases, were recruited to speak about their personal experiences. Venues included Boston Med Center, Tufts Med Center, Hasbro Children’s Hospital, Baystate Med Center, and Maimonides Med Center. Several presentations were video-recorded

either in full or in 5-7 minute versions for easier accessibility. Feedback from audiences has been universally enthusiastically positive.

2. *"Making the Move: Mapping YOUR Best Route to Adult Sickle Cell Care"* by Bill Kubicek and Hilary Gerson of Next Step. \$22,000 in funding was provided for three workshops (in Rhode Island, Massachusetts, and Connecticut) to educate 29 young adults with sickle cell disease about the transition process into the adult care system. Completed workshop evaluations indicated that participants were glad they attended, would recommend the program to a friend, and had learned something new.
3. *"Thyroid Dysfunction: Long Term Follow-Up of Very Low Birth Weight and Extremely Low Birth Weight Infants"* by Dr. Chanika Phornphutkul. \$32,000 in funding was provided for conducting a study on congenital hypothyroidism (CH) and its relationship to delayed thyroid-stimulating hormone (TSH) among very low- and extremely low- birthweight infants. Through an analysis of 65,000 births over 5 years of data, project staff concluded:
  - ❖ Incidence of CH with delayed TSH surge is higher among ELBW infants.
  - ❖ Most infants with delayed TSH surge have transient CH
  - ❖ Growth and neuro-developmental outcomes of ELBW infants with CH and delayed TSH surge are comparable to matched controls
4. *"Meeting the Challenge of Identifying Urea Cycle Disorders by Newborn Screening"* by Dr. Margretta Seashore. \$20,000 in funding was provided for conducting a more intensive review of screenings for Urea Cycle Disorders to determine if children have been missed by newborn screening and, if so, what factors may have contributed to false negative findings.
5. *"New England Connection for PKU and Allied Disorders Implementation of Strategic Plan"* by Denise Queally and Donna McGrath. \$4,000 in funding was provided for Denise Queally to support a range of design and communication improvements to the NECPAD website. As a result, Denise notes that the grant opportunity has helped them become more technically savvy, self-supportive, and more attractive to younger generations. The updated website can be viewed at [www.necpad.org](http://www.necpad.org).

For final reports submitted by each of the above grant recipients, please visit the NEGC website at: <http://www.negenetics.org/innovative.html>.

## **Supporting the National Coordinating Council**

The NEGC have representatives in each NCC Work Group:

- Telegenetics Work Group: Rosemarie Smith
- Emergency Preparedness: Roger Eaton
- Newborn Screening: Anne Comeau
- Evaluation: Peter Antal
- Website: Amy Schwartz
- Communications: Amy Schwartz
- Provider Network: Anne Comeau

## WORKGROUP ACTIVITY IN YEAR TWO

This section provides an overview description of each working group's activities during Year Two. For an across-the-board view of major highlights from each group, please see Appendix D. A record of when groups met during the course of the year is provided in Appendix E.

### **The Quality Improvement Working Group**

The QI Working Group has seven members and is led by NEGC Principal Investigator, John Moeschler, M.D. They met in October and December of 2008 and again in March of 2009.

During the project's second year, workgroup members further refined the pilot project, defined data sets and a data dictionary for each participating center, and identified and mapped clinical genetic outreach sites. Discussions continued to evolve around when center studies should be run for which patients, appropriate panel use and MRI imaging. Members agreed to adopt a common approach for process and outcome measures related to genetics health care improvement in order to compare and contrast results across four sites (Vermont Regional Genetics Center at UVM, DHMC in Lebanon NH, Maine Medical Center in Portland and Children's Hospital Boston). Piloting of the data collection tool has begun and an interim report is expected in August.

Efforts focused on developing a common understanding of defining patients/customers and how the group is making a difference in the lives of patients. In addition to work on improving the quality of data across systems, staff also participated in a webinar with David Ledbetter to review work with the International Standard Cytogenomic Array Consortium and his proposal to establish a public database. Members reviewed the webinar information in light of how his work could be applied to existing practices.

Additionally, staff have received IRB approval from Dartmouth and UNH for analyzing DHMC billing data, continued to pursue and address IRB and HIPAA requirements around the development of a genetics registry, completed the framework of the proposed registry, begun coordination efforts with the Medical Home and Transition Workgroup, and have begun work with national counterparts to ensure developments of the registry are in line with national standards and the development of the Newborn Screening Translational Research Network.

### **The Transitions Working Group**

The Transitions Working Group is led by Dr. Susan Waisbren, who is also the leader of the National Transitions Working Group. Dr. Waisbren has been working with a subgroup of the New England Consortium of Metabolic Programs to conduct the work of the group. This subgroup met eight times during Year Two. Six members of this subgroup also participated in the monthly conference calls for the National Transition to Adult Care work group which met nine times.

#### *Regional Workgroup Activities*

Assess willingness and ability of providers to provide adult care.

Surveys conducted in New Hampshire and Rhode Island of primary care physicians documented the need for better communication between specialty clinics and community providers as well as written transition plans.

#### Distribution of PKU Toolkit

Over 100 toolkits have been distributed in New England as well as in Metabolic Clinics and the International Conference for Adults and Teens with PKU.

#### Teen Challenge for Adults with Metabolic and Other Genetic Disorders

A 4 Day Teen Challenge was held, educating 18 teenagers about maternal PKU, the psychological effects of discontinuing treatment, and the need to take responsibility for their care. Participants received copies of the PKU Toolkit and talked about how they could better explain PKU to their community healthcare providers.

#### Patient Survey: Metabolic Clinic at Children's Hospital Boston

As a result of survey work with 35 patients at Children's Hospital Boston and staff follow-up with patients, 28 adult patients, most of whom had not been seen in over 5 years, were scheduled with new appointments at the clinic.

#### *National Workgroup Activities Supported by the NEGC*

#### International Conference for Adults and Teens with PKU and Allied Disorders.

220 people registered for this event with 95 teens and adults with PKU involved. This was the largest gathering of adults with metabolic disorders ever to be held in the U.S. and shared information on topics such as “Straight Talk about Thinking Straight”, “How PKU Sometimes gets in the Way and What to do About it”, “Transition and Self-Advocacy” and “A Case Study of Weight Loss and PKU”. A survey of participants showed several without a primary health care provider, or who did not have insurance to cover formula / foods. Of 27 under age 25, only one participant had a transition plan in place. The three highest rated activities included networking and social activities, the maternal PKU breakout session and the discussion of adult topics related to PKU.

### **Medical Home Working Group**

In June 2008, the Medical Home Working group officially formed under the direction of Dr. Carl Cooley. The diverse membership of 19 includes primary care physicians with medical home experience, specialists from regional metabolic disease programs, and parents of children with metabolic disorders. The group also met in Oct. 2008 and again in March, 2009.

The first meeting of the Medical Home Working Group was held June 18, 2008. At this meeting, participants addressed the issue of how PCPs and genetic specialists can work together more effectively. The participants noted that one way to deal with the shortage of genetic specialists is to have PCPs take on more of the care of metabolic patients. The participants also surfaced ideas about how to implement this expanded role. First, PCPs would need more guidance from specialists about what types of care they should and should not be attempting. Second, PCPs would also need more health and related information from the specialist in order

to comfortably provide appropriate services. During their discussions, the workgroup agreed on two core definitions:

*Quality Newborn Screening* – Each infant diagnosed with a heritable disorder should be linked to a primary care doctor and followed for several months, to assure appropriate care.

*Expanded definition of Medical Home* – The current definition of Medical Home is that each newborn with a positive screening test is linked to a primary care provider. The NEGC would like to expand this definition to the one adopted by the Maternal and Child Health Bureau and the American Academy of Pediatrics.

During 2009, work began to focus on the development of a dynamic care planning instrument which could be used as a communication tool among specialists, families, and the primary care medical home. This tool would contain current clinical information, decision support guidance for the medical home, and explicit definitions of roles among specialists, primary care physicians, and families. In following up on the creation of a draft tool with Dr. Chris Still at UMass Medical Center, the workgroup chair provided several presentations in the region to lay the groundwork for a proposed pilot. The workgroup crafted and applied for funding to support a year-long pilot project that would field test the planning tool, collect recommendations and data and, ultimately set the stage for a larger implementation grant application to the Maternal and Child Health Bureau in Aug. 2010.

### **Dissemination, Education, and Marketing Working Group**

The eight members of this Working Group are led by Dr. Leah Burke. During Year Two, major activities of the group focused on updating/distributing materials, completing work from the New England Public Health Genetics Collaborative (NEPHGC), and working with special educators to help them better understand genetic issues and how they impact the children they serve.

#### *Distribution of Materials*

These include the Guide to Understanding Genetics, Newborn Screening Brochures, and Common Chronic Diseases. All materials developed by any working group are posted to the NEGC website and staff work to ensure that products are sent to agencies or constituents who may have a particular interest.

#### *Completion of New England Public Health Genetics Collaborative Work*

This included work on incorporating genetic consultant feedback into the toolkits, completing the Spanish translation of New England resources, and updating the Family History Module.

#### *Resources for Special Educators*

As a result of a review of the challenges that can arise in a special education setting when teachers are working with children with genetic conditions, Anne Dillon OTR, M ED., from the IOD/UNH created an informational tool that can provide teachers with a better understanding of how they can create a better and more inclusive classroom for their students with genetic conditions. Building on this effort, workgroup members sought to gather feedback from special educators on the types of information that would be most needed. After substantive discussion throughout the year on building a survey to document need and likely use of the tool, the decision was made to alter the survey approach and focus instead on a series of focus

groups to elicit more hands-on reactions to the chart that could then be used to more effectively guide the tool's improvement. A half-day meeting is planned with NEGC staff and the UNH Survey center to discuss focus group content and next steps for the committee to advance the project.

### **Laboratory Quality Assurance Working Group**

The Laboratory Quality Assurance (QA) Working Group has two members and is led by Dr. Roger Eaton. The two members work regularly in collaborations between the New England Newborn Screening Lab and other state labs based in New York, Connecticut, and Wisconsin. Members of the working group as well as members from the participating states participated in a day-long conference in May 2008 to review findings and plan next steps.

During Year Two, all four labs have collected information on propionylcarnitine (C3) elevations, including information on concentrations of markers of specimens with out-of-range C3 results, and information regarding the diagnosis assigned to the each of the babies by each lab's follow-up branch. As a result of their analysis using the New England Newborn Screening Program (NENSP)- defined indices and cutoffs to the collected data sets, the working group determined:

- ❖ Promising developments have been observed via the monitoring of C5, C5:1 and C4 levels as these demonstrate slightly different levels in true cases (compared to false positive C3 elevations)
- ❖ When applying cut-offs to the work of other labs (non NENSP), it was determined that the effectiveness of categorizations was somewhat diminished as a result of differences in lab approaches. As a result, lab specific cut offs will need to be determined in order to make best use of the indices. In order to create meaningful lab specific cut offs, the workgroup will further analyze population data from all markers at each laboratory and use the population-based statistical parameters to guide determination of laboratory specific cut-offs. This work has been completed for NY and WI for C3.
- ❖ Work to date has shown much promise and supports the further expansion of the protocol to other indices and markers

### **Long Term Follow-Up Working Group**

The Long Term Follow-Up (LTFU) Working Group has 10 members and is led by Dr. Anne Comeau. The full group met three times during Year Two, the Hgb workgroup met three times and the CF workgroup met once.

#### *Regional Charter Agreement*

Education and state team support. In addition to communications about LTFU with state team leaders, regional presentations were made by the workgroup chair, Dr. Anne Comeau, to the Newborn Screening Advisory Committees in Maine, Rhode Island, New Hampshire and Vermont. The presentations focus was educational and interactive; Maine, Rhode Island and Vermont had each set aside about 1 hour of their agendas for the topic. The Maine and Rhode Island NBS Advisory Committees renewed support for LTFU activities for communication to their state's legal representatives. The New Hampshire NBS Advisory Committee indicated misgivings about being able to participate given the NH infrastructure and budget. The Vermont NBS Advisory Committee had called in special legal representation for their meeting but the representative was called out of the meeting before any recommendation was issued.

Legal steps toward regional agreements. Two states made significant progress in formalizing legal authority or interpretation of rules related to LTFU as a direct result of educational efforts. Massachusetts promulgated regulations requiring that providers respond to requests from the NBS program for LTFU data and Maine interpreted its rules so that providers could respond to requests from the NBS program for LTFU data as they do for STFU data. The LTFU workgroup held a daylong meeting with state legal representatives regarding interstate data sharing and privacy issues relating to Long Term Follow-Up (LTFU) of Newborn Screening (NBS). Following the daylong meeting, a conference call between MA and ME legal or privacy officers yielded agreement that Maine would go forward with the LTFU plans in collaboration with NENSP as outlined in the proposal. Rhode Island reports significant progress: intrastate agreements for LTFU activities that previously were not in place are moving forward as the first step to participation with the NENSP on the project outlined in the proposal.

#### *Test of Feasibility of Data Collection*

The LTFU Workgroup had agreed to use the Massachusetts data collection variables developed by the Massachusetts CF, Hgb or Metabolic Workgroups as a starting point for regional data collection. The group also determined priority data elements, the highest of which was “census data”.

Census data: Following agreements described above, NENSP (for MA) and Maine NBS programs collected and analyzed information about the patients diagnosed since 1999 through the respective newborn screening programs for CF, Sickle Cell Disease and Metabolic conditions. Data was acquired from subspecialty clinics and from primary care providers and included information as to whether the child was alive or dead, the date of the last subspecialty visit, and other clinical system review. Aggregate data have been provided to clinical workgroups. Patient-specific data requiring action has prompted intervention with some success (e.g. some children who had not seen a subspecialist in years now have appointments). These data were reported to the Data collection workgroup, to the Secretary’s Advisory committee and comprise the major subject of a manuscript requested for publication in Genetics in Medicine Supplement.

Members of the NENSP’s NBS Hgb Workgroup have agreed on a common set of LTFU clinical variables. Within this regional Workgroup, the subspecialty clinics in MA and RI have begun active data collection and some of these data contributed to the census information. Available clinical data are being processed.

#### *Supporting Changes in the Field*

During Year Two, Dr. Anne Comeau provided presentations or hosted major events highlighting the importance of LTFU and needed changes in the field. These include: the National Data Collection and Long Term Follow Up Workgroup in Washington, DC, 2008 Newborn Screening and Genetic Testing Symposium meeting, the Newborn Screening Molecular Training Workshop, and the Secretary's Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children in Washington, DC.

#### *Long Term Psychosocial Follow-Up of Newborn Screening*

Dr. Susan Waisbren and Dr. Joanna Fanos led work on psychosocial follow up during Year Two.

Sustaining the Psychosocial Follow-up Working Group. Membership of the group has been updated, with 13 members participating across three sub-groups: Cystic Fibrosis, Hemoglobin, and Metabolic.

Developing an Informed Understanding of Psychosocial Implications of Diagnosis for Families. All 13 members of the working group were interviewed to gather and learn from provider experiences in working with families of children with genetic conditions. Topic areas addressed include: implications of late vs. early diagnosis, false positives and ambiguous results, well siblings of newly diagnosed infants, provider satisfaction with initial meetings, educational materials on newborn screening, internet use by parents, risk to attachment relationship of parent and child, parental level of understanding of diagnosis, importance of language in communication with parents, anxiety and depression and identification of available coping resources, long term follow up of newborn screening. As a result of the interviews the following recommendations were made:

- ❖ For qualitative assessment for long- term psychosocial follow-up, clinic staff should query parents over time as to their expectations for their child. In addition, asking parents over time about their anxieties would also be very informative.
- ❖ Educational materials should be developed for each state with some degree of standardization where appropriate (e.g., descriptions of disease, etc).
- ❖ Workshops should be offered in effective communication about newborn screening results with families. For example, a member of the Psychosocial Working Group, Maria Trozzi, M.Ed. (Boston Medical), a national expert on best practices in communicating difficult news to parents, could provide excellent training, either directly or through training medical staff.
- ❖ Research should be conducted to study parents who have an infant diagnosed through newborn screening to identify their needs, and how best to address them.

Psychosocial Assessment Tool for Non-Psychologists. In response to a national need for a reliable, readily accessible assessment method that can be administered by non-psychologists to aid in the successful transition plan for youth entering the adult care system, a newly formed national group (Metabolism and Genetics Psychology Network) led by Dr. Waisbren (Children's Hospital Boston) and Dr. Desiree White (Washington University in St. Louis) has reached consensus on the selection of a set of published instruments based on their reliability, validity, accessibility for non-psychologists, consistency across various ages and cultures, and ease of scoring and interpretation. These instruments comprise the Uniform Assessment Method which will enable information to be obtained inexpensively, scored and interpreted via computerized systems, and easily incorporated in a database for long-term follow-up as well as in a Transition Plan. An added benefit of this project will be that all patients in New England can receive the same set of evaluations. In the future, retrospective studies can be conducted on a regional basis to evaluate the outcome in adolescents and adults with a specific metabolic or genetic condition. Moreover, the results are expected to be extremely useful for data registries which are being considered for genetic and metabolic disorders.

Summary Consumer Information Form. An additional area of work has been with the Consortium Planning group to create a summary information form that will be part of the Transition Packet that each patient will use when visiting their adult care provider or adult specialty clinic. The form will first be piloted at Children's Hospital, Boston, refined and then exported to other clinics in New England.



- ❖ Outcome Measure A1: Increase in the percentage of states/territories in the region with collaborations facilitated by the Regional Collaborative between PCPs and specialty (including genetic) providers to improve care coordination for people with heritable disorders.
- ❖ Outcome Measure B1: Increase in the number of genetic services visits and NBS follow-up specialty visits provided to individuals/families through distance strategies implemented by the regional collaborative.
- ❖ Outcome Measure C1: Increase in the percentage of states/territories in the region that have received current materials or other assistance from the RC on emergency preparedness/contingency planning for newborn screening (NBS) and genetic services.
- ❖ Outcome Measure D1: Increase in the percentage of states/territories in the region that have evaluated and made recommendations on implementing the ACHDGDNC recommended NBS panel.
- ❖ Outcome Measure E1: Increase in the percentage of states/territories in the region with systems in place to track entry into clinical management for newborns who are diagnosed with condition(s) mandated by their State-sponsored newborn blood spot screening programs.
- ❖ Outcome Measure E2: Increase in the percentage of states/territories in the region with systems in place to track entry into clinical management for newborns who are diagnosed with hearing loss through their State-sponsored newborn hearing screening programs.
- ❖ Outcome Measure E3: Increase in the percentage (number) of states/territories in the region with systems in place to track receipt of clinical services and/or health outcomes for children who are diagnosed with condition(s) mandated by their State-sponsored newborn blood spot screening program and/or with hearing loss through their State-sponsored newborn hearing screening programs.
- ❖ Outcome Measure F1: Increase in the percentage of states/territories in the region whose NBS programs disseminate “just-in-time/point-of-care” information on specific heritable disorders to primary care providers (PCPs).
- ❖ Outcome Measure G1: Increase in the percentage of Regional Collaboratives that have completed a regional genetic services plan.
- ❖ Outcome Measure G2: Increase in the percentage of Regional Collaboratives that have reviewed and/or updated their regional genetic services plan at least every two years.

## **NEGC Stakeholder Survey**

For Year 2, the evaluator again worked with project staff and collaborative council members to update and implement the NEGC stakeholder survey. The survey was administered online between May and June 2009. A summary of the results follows.

### ***SUMMARY OF FINDINGS FROM THE YEAR TWO STAKEHOLDER SURVEY***

*(Executive Summary excerpted from New England Genetics Collaborative, Results of the Stakeholder Survey for Project Year Two by Peter Antal, Ph.D. (September, 2009). For the full report, please download from [www.negenetics.org](http://www.negenetics.org))*

Between May and June 2009, 68 email invitations were sent out to stakeholders of the New England Genetic Collaborative (NEGC). Of these, 20 (29%) provided responses. Stakeholder feedback offers a series of helpful insights into the potential next steps for the collaborative as it carries on activities for project year three. Respondents suggested new spotlight projects as well as resources to be mapped out on the NEGC website, documented multiple strengths of the collaborative's membership (particularly in regards to the collaborative spirit, commitment and leadership), and identified areas where continued support from the

NEGC is needed. Feedback on the project's evaluation reports were generally positive with 9-12 out of 16 indicating that each of the reports helped readers understand the progress and challenges of the initiative.

In several areas of the survey agreement ratings were mixed. On the topic of appropriate NEGC involvement with service providers/decision makers and consumers, about a third of respondents agreed with the statement while one in four disagreed and the rest were neutral. When asked whether they had a clear understanding of the NEGC's mission, 12 of 20 respondents agreed. Concerning whether the NEGC had made substantive and clear progress in achieving its mission, nine agreed, six were neutral and four disagreed.

When asked about the strengths of the collaborative, several common themes emerged across all survey respondents, highlighting: the collaborative spirit, commitment to the mission, leadership of key individuals, administrative support by Karen and Amy, experience of members, communication and open discussion, varying viewpoints and presentation of ideas, clear objectives, common mission, and other.

Concerning some of the obstacles faced, the most frequently cited challenge was time needed for greater involvement in the project, followed by concerns about interactions among members, barriers to utilization of health information technology, lack of fiscal resources, length of time between meetings, geographical limitations, and other.

Respondents were also asked about what the NEGC could do to provide better support. In response, most members focused on the continued need for administrative support (managing due dates, grants, papers, IRB applications), technical support for handling new technology, improved communication, finding new opportunities for members to collaborate on, leadership, and other.

## **COMPLETION OF OBJECTIVES IN YEAR TWO**

The following table provides a complete list of the objectives set forth by project staff at the beginning of the project year (with some modifications) as well as the status of each objective as of June, 2009. Measures of objective “status” are defined by the following key: 1. Completed as planned, 2. Completed - deviated substantially from plans, 3. In progress - satisfactory, 4. In progress - unsatisfactory, 5. Initiation of activity deferred, 6. Activity abandoned, 7. Not scheduled to initiate this period, 8. Insufficient documentation available.

<b>ESTABLISH AND MAINTAIN NEGC</b>			
<i>No.</i>	<i>Objective</i>	<i>Status</i>	<i>Comment</i>
1	Continue close collaboration with WG and AC	3	Meetings are held regularly and supports provided when requested as resources allow.
2	Maintain and update website	3	Website is maintained and updated continuously.

3	Continue communication and engagement (formal and informal) with key stakeholders and interested consumers	3	Multiple methods in place to communicate with stakeholders, both direct (email, phone, web conferences, annual stakeholder survey), and indirect (website)
<b>QUALITY IMPROVEMENT</b>			
<b>No.</b>	<b>Objective</b>	<b>Status</b>	<b>Comment</b>
1	Implement pilot project to improve diagnostic outcomes of those with global developmental delays or intellectual disabilities living in rural areas	3	Goals identified, partners identified, agreement on process and outcomes data to be used
2	Develop database to evaluate pilot project outcomes	3	Data sets refined, data dictionary developed, assessments of reporting mechanisms at each center conducted.
3	Improve the level of metabolic disease awareness at medical centers through the Metabolic Outreach Service	6	Initiative undertaken by innovative project led by Dr. Mark Korson.
4	Develop mechanisms for long-distance consultation regarding diagnosis and management of metabolic patients through the Metabolic Outreach Service	6	Initiative undertaken by innovative project led by Dr. Mark Korson.
5	Provide educational opportunities in metabolism for medical students and residents and encourage formal training in biochemical genetics through the Metabolic Outreach Service	6	Initiative undertaken by innovative project led by Dr. Mark Korson.
6	Catalog outreach sites for Clinical Genetics in New England	1	Sites identified and map made accessible on project website.
7	Partner with Federally Qualified Health Centers to reach the vulnerable, underserved, and hard to reach populations	5	Activity deferred

**TRANSITION**

<i>No.</i>	<i>Objective</i>	<i>Status</i>	<i>Comment</i>
1	Assess willingness and ability of providers to provide adult care	3	Survey of clinics (not PCPs) documented lack of adult care providers. Some targeted work with expanding services at Brigham and Women's Hospital. Recruited additional partners from Sickle Cell and CF.
2	Hold conference on transition to adulthood	3	A Conference for adult patients with Galactosemia will be held in August 2009.
3	Release PKU model toolkit	1	Patients and providers have been very receptive and feedback has been positive. Continue to distribute
4	Hold conference for young adults with PKU	1	Held in August, 2008: 90 adults with PKU and 200 participants
5	New: Joint work with medical home	3	Dr. Cooley presented at our Planning Group. Questionnaires being developed.
6	New: Coordination with national efforts	3	Continue monthly conference calls. Added New England members from Sickle Cell and CF communities.

**MEDICAL HOME**

<i>No.</i>	<i>Objective</i>	<i>Status</i>	<i>Comment</i>
1	Identify a feasible pilot for improved care coordination and communication	3	Children's Boston agreed to participate, three other sites considered (Tufts, UMass, Maine Medical Partners). Pilot design outlined in narrative of Yr 3 Reapplication.
2	Apply for mini-grant funding of pilot project	1	Application submitted by Dr. Christopher Stille, Multiple conversations underway with key partners to move medical home project forward.
3	Begin field test of the care coordination project in two specialty clinic catchment areas	5	Field test to begin in 2009.
4	Form broad-based medical home work group	1	Medical Home workgroup convened.

**DISSEMINATION, EDUCATION AND MARKETING**

<i>No.</i>	<i>Objective</i>	<i>Status</i>	<i>Comment</i>
1	Continuously improve educational products and activities	3	Products updated/disseminated: Newborn Screening Patient Toolkit, New England Resources Directory, Understanding Genetics Guide for Patients and Professionals, Family Health History Presentation All products developed by DEM and other NEGC collaborations will be posted and dissemination strategies initiated
2	Evaluate the utilization and impact of the Genetics Outreach Project for community health centers	6	This effort was tabled due to duplication of work from the New England Resource Directory.
3	Assess the needs of educators in the public sector	3	Survey tool created and fielded for Anne Dillon's chart. Additional work centered on conducting regional focus groups to further update the tool.
4	Develop educational resources for public educators	3	In collaboration with Ann Dillon, flow chart developed to assist educators in their work with children with genetic conditions

#### **DEMONSTRATE EFFECTIVE COLLABORATIONS**

<i>No.</i>	<i>Objective</i>	<i>Status</i>	<i>Comment</i>
6.1	NEGC continues to participate in national work groups	3	National Groups: NCC, Telegenetics, Emergency Preparedness, Newborn Screening, Evaluation, Website, Communication, Provider Network,
6.2	Catalog WG and AC member participation in national groups	3	Ongoing.
6.3	Link with affiliated programs (LEND and AUCD)	3	Efforts coordinated with David Helm and John Moeschler.
6.4	Represent genetics issues to wider healthcare system	1	Staff is presenting to groups re: healthcare and genetics policy, presentation developed and archived. Audiences include academic institutions, presentation available on the NEGC website

#### **INNOVATIVE PROJECTS PROGRAM**

<i>No.</i>	<i>Objective</i>	<i>Status</i>	<i>Comment</i>
1	Monitor innovative grant awardees	3	Ongoing.

2	Work with grantees to develop poster presentations	1	Poster presentations created for Yr 1 grantees.
3	Confirm award amount and issue RFP for grant cycle 2	1	Completed.

**LABORATORY QUALITY ASSURANCE**

<i>No.</i>	<i>Objective</i>	<i>Status</i>	<i>Comment</i>
1	Continue development of collaborations with other states	1	Collaborations in place with labs in New York, Wisconsin, and Connecticut to test algorithms.
2	Conduct data analysis using additional MSMS markers	3	Analysis of C3 continued. A small number of unexpected discrepancies noted in one dataset (New York) – several disorders normally associated with C3 elevations had normal C3 levels. NY noted that lab always had doubts about the diagnoses on these cases. Is looking back at original data to examine basis for diagnostic determination. Raw statistical data on normal data requested and submitted by each lab to examine optimization by calculating lab-specific index cutoffs. CT acquired and began using Perkin Elmer’s Specimen Gate software in 2008. This is very good news as it will permit CT to participate fully in project (original proposal noted that CT would need to participate on a more limited basis due to database limitations). Case was argued and accepted by collaborating group that statistical data analysis of CT data must wait for 50,000 samples analyzed using Specimen Gate. This will be ready August 2009. Data being collected on other markers
3	Convene collaborative conference September/October 2008	2	Conference held Spring 2009. Detailed review of all NENSP indices presented. Partner labs invited to suggest additional indices. All labs liked NENSP indices and group consensus was to proceed with original indices proposed by NENSP

**LONG TERM FOLLOW-UP**

<i>No.</i>	<i>Objective</i>	<i>Status</i>	<i>Comment</i>
1	Complete Regional Charter Agreement	3	Working through many of the basic definitions and understandings and reviewing key operating principles relevant to our current and future regional system. Presentations made to state NBS advisory meetings. Except for CT, all states in the region appear to be moving forward at varying levels. Data flow presentation developed and presented to Maine, Vermont, and

			New Hampshire.
2	Test of feasibility of data collection approach using NENSP LTF variables	3	Tracking of children identified with CF, Hgb, and metabolic disorders born 1999-2008 is ongoing. Data collection tools are being evaluated for optimal use and feasibility.
3	Define the quality assurance minimum dataset	3	The minimum data set elements are child's name, confirmation of continued care and date of last specialty clinic visit.
4	Test of feasibility/census	3	Census of children identified with CF, Hgb, and metabolic disorders is in progress and has involved extensive and multiple contacts to both specialty clinics and Primary Care Providers.
5	Evaluation of follow-up support services	6	This is an activity that the NCC indicated that they would be doing.
6	Refine dataset variables per condition-specific needs	3	New England Hgb Workgroup started data collection, New England CF; New England Metabolic; Psychosocial workgroups refining variables.
7	Feasibility evaluations: data variables	3	Dr. Comeau presented preliminary data at the February 26, 2009 Secretary's Advisory Committee. Manuscript is in preparation.
8	Feedback to centers	3	Reports to centers in progress detailing initial census data including numbers lost to follow-up, numbers not followed at specialty clinics, and center to center transfers. Presentation scheduled in August 2009 to New England Hgb Workgroup. Regional CF Workgroup meeting was held in November 2008.
9	Address "lost to follow-up" issues	3	For children receiving regular care by a Primary Care physician but were lost to follow up to specialty clinics, recommendation was made that children should be seen at treatment center. Center to center transfers continue to be a challenge that is being addressed so as not to count these children as lost to follow up. Verification and documentation of moves (both within and out of region) by both Primary Care Providers and specialty clinics are often incomplete.
10	Participate in Interregional and NCC workgroups	3	Ongoing, 2008 Newborn Screening and Genetic Testing Symposium, Newborn Screening Molecular Training Workshop, National meeting of psychologists with Dr. Waisbren (administration of tools by non psychologists - Metabolic Clinic at Children's Hospital may follow up), Creation of: Genetics and Metabolism Psychology Network
11	Convene Regional Policy and HSR conference	3	The NBS LTFU Workgroup hosted a successful meeting in May 2009 to address data sharing policy issues and is on track to addressing privacy concerns. Legal Representatives from each New England state were invited to attend. Further follow up between MA, ME, and RI is ongoing.
12	Special Projects Concentration – Psychosocial follow up	3	3 Groups formed (CF, Hgb, Met), literature review conducted, individual interviews conducted, questionnaires identified for use by non-psychologists, forms also developed for adults as well as informants, new permanent group formed (Genetics and

			Metabolism Psychology Network).
<b>QUANTITATIVE AND QUALITATIVE EVALUATIONS</b>			
<i>No.</i>	<i>Objective</i>	<i>Status</i>	<i>Comment</i>
1	Gather data on program activities and outcomes and provide ongoing feedback to project staff and funder on project progress.	3	Feedback provided on ongoing basis, weekly updates provided to management staff.
2	Conduct annual stakeholder survey	3	Yr 1 Stakeholder survey completed and report created.
3	Complete semi-annual and annual reports which can be used by staff to improve project outcomes	3	Yr 1 Report and Yr 2 Mid-Yr report completed.
4	Participate on national outcome measurement efforts	3	Ongoing.

## **OBJECTIVES FOR YEAR THREE**

The following tables provide a list of objectives to be completed by each of the relevant workgroups and administrative teams for Year Three of the NEGC project. The status of each objective will be updated by the Project Manager on a monthly basis during meetings with the various Working Group chairs using the following key: 1. Completed as planned, 2. Completed - deviated substantially from plans, 3. In progress - satisfactory, 4. In progress - unsatisfactory, 5. Initiation of activity deferred, 6. Activity abandoned, 7. Not scheduled to initiate in period. As a result of previous discussions on the need for measurable outcomes in each goal area, workgroup chairs have established a series of performance measures to document successful achievement of each of their objectives.

### Goal 1: Establish and maintain the NEGC

*Led by: NEGC MANAGEMENT STAFF*

<i>Obj.</i>	<i>Objective for Year 3</i>	<i>Definition of Success</i>	<i>Measurement of Success</i>
1	Continue close collaboration with WG and AC	Work Group and Advisory Council members feel supported in the work they do and have access to the resources they	Satisfaction scores as measured by the annual Stakeholder Survey. Advisory Council chair

		need to accomplish their goals.	participates on the Collaborative Council
2	Maintain, update and enhance NEGC website	<p>The NEGC stays current with state, regional, and national level developments.</p> <p>Stakeholders have information necessary to keep informed of all project developments.</p> <p>Website is utilized by growing numbers of individual users.</p>	Web logs, Stakeholder Survey, Social Networking functions.
3	Continue communication and engagement (formal and informal) with key stakeholders and interested consumers	Stakeholders report satisfaction with being able to voice their opinions and feel that they've been heard.	Stakeholder Survey.

Goal 2: Collaborate to facilitate access to genetics services, expertise and technology particularly for underserved populations and in rural areas.

Led by: *QUALITY IMPROVEMENT WORKING GROUP*

<i>Obj.</i>	<i>Objective for Year 3</i>	<i>Definition of Success</i>	<i>Measurement of Success</i>
1	<ul style="list-style-type: none"> <li>Implement clinical genetics pilot registry to aggregate clinical outcomes data</li> <li>Complete utilization data analysis for one site</li> <li>Obtain IRB / CPHS approval for utilization data analysis at all sites (NH, VT, MA, ME).</li> <li>Begin utilization data analysis</li> <li>Submit for publication white paper on utilization of genetics services.</li> </ul>	<p>By end of Q2, all five sites will be entering data each week or month.</p> <p>By end of year, all five sites will be entering data on 100% of appropriate patients.</p> <p>Data report format completed</p> <p>Data by site and region reported on website</p> <p>Publication submitted</p>	<p>No. of sites submitting.</p> <p>No. of sites submitting weekly or monthly (TBD which sites, which frequency)</p> <p>100% of patients by random chart review sample at 2 sites.</p> <p>Yes/ No</p> <p>Yes/No</p> <p>Publication submitted.</p>
2	<ul style="list-style-type: none"> <li>QI data submitted, analyzed and reported from all four current clinical genetics sites.</li> </ul>	<p>Data base in place.</p> <p>See above</p>	<p>Data base in place.</p>
3	<ul style="list-style-type: none"> <li>Meet with one to three FQHC's to identify problems with access to clinical genetics services.</li> <li>Develop method for assessing needs of FQHC's in 2 states.</li> <li>Assess the capacity of FHQC's and representative public health clinics in NE to identify those patients in need of referral to a clinical genetics unit. This will require literature review, focus group and possible short survey tools.</li> </ul>	<p>Meet with one FQHC by end of Q1, second Q2, third Q3.</p> <p>Presentation and focus group meeting at 3 FQHC's in NE.</p> <p>Results summarize d by end of year.</p>	<p>Mgmt meeting minutes.</p> <p>Areas of need for improving access to genetics services for those served at FQHC written.</p>
4	<ul style="list-style-type: none"> <li>Convene one "Breakthrough Learning Series" in quality improvement for NE Genetics Centers, based on the Institute of Healthcare Improvement using the existing four sites and with the purpose of rapid dissemination to other NE Centers. One</li> </ul>	<p>Was funding identified through ARHQ or other source to support activity</p>	<p>Funding identified.</p> <p>Planning group identified.</p> <p>At least one other RC partner signed up.</p>

	face-to-face meeting with 3 webinars will be completed. We will target urban academic or private clinical genetics practices from Boston, Worcester, Providence, New Haven, etc.		
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Goal 3: Develop effective practice models for adolescents and young adults with genetic conditions who are transitioning from pediatric to adult health care.

*Led by: TRANSITIONS WORKING GROUP*

<b>Obj.</b>	<b>Objective for Year 3</b>	<b>Definition of Success</b>	<b>Measurement of Success</b>
1	Assess willingness and ability of providers to provide adult care	Contact with a medical home	Written agreement (working with Carl Cooley)
2	Hold conference on transition to adulthood	Conference takes place	Report on Conference
3	Create materials for women with galactosemia about premature ovarian insufficiency	Materials are published	Materials
4	Hold conference for adults with galactosemia	Conference takes place	Report on Conference
5	Complete comprehensive review of transition practices	Review completed by 9/09	Review published on website.
6	Create transition best practice protocol and customize for metabolic patients	Protocol defined by 12/09	Meeting Minutes
7	Pilot transition practice(s) protocol in one metabolic clinic	Pilot project initiated by 1/10	Meeting Minutes
8	Leadership training for teens with genetic disorders. Program at Teen Challenge Weekend	Leadership training takes place	Report on training

Goal 4: Develop effective partnerships to further Medical Home practices in the region.

*Led by: MEDICAL HOME WORKING GROUP*

<b>Obj.</b>	<b>Objective for Year 3</b>	<b>Definition of Success</b>	<b>Measurement of Success</b>
1	Design suitable care planning tool for the care coordination pilot	Completion of a prototype care planning tool.	Tool is ready for using in two or more specialty clinic pilot sites during Year 3.
2	Begin field test of the care coordination project in two specialty clinic catchment areas	At least two specialty clinics have implemented a care planning tool with at least 10 patients each.	Clinic coordinators will log care plans and track achievement of planning goals for each patient.  Families, specialty team members, and primary care practices will be surveyed regarding satisfaction with the care planning tool.
3	Convene at least 3 meetings of the MHWG during Year 3	Two conference calls and one face to face meeting happen during Year 3.	Meeting agenda and minutes document content and attendees.

GOAL 5. RCC will serve as the focal point for effective genetics education and dissemination of genetics information.

*Led by: DISSEMINATION, EDUCATION AND MARKETING WORKING GROUP*

<i>Obj.</i>	<i>Objective for Year 3</i>	<i>Definition of Success</i>	<i>Measurement of Success</i>
1	Continuously improve educational products and activities for special educators in the public school system	Compile the information to be used to populate the fields on the informational flow chart	A working model of the informational chart in electronic form
2	Assess the needs of special educators in the public sector	Deploy the survey to special educators	The specific data from the survey
3	Develop educational resources for special educators	Develop continuing education modules for special educators on genetics	Completed modules for continuing education
4	Improve utilization of already developed tools:  Newborn Screening Patient Toolkit, New England Resources Directory, Understanding Genetics Guide for Patients and Professionals, Family Health History Presentation	Promote increased utilization of educational tools developed in the past years by improving their electronic accessibility	Increased utilization as tracked electronically through the website

RCC will demonstrate effective collaborations with other regional and national stakeholders, such as the National Coordinating Center, the National Newborn Screening and Genetics Resource Center, CDC-

sponsored Centers of Excellence for Birth Defects Prevention Research, CDC Newborn Screening Branch, NICHD, AAP, University Centers of Excellence in Disability (UCEDD's), MCH Leadership Education in Neurodevelopment Disability Education programs (LEND programs), etc.

*Led by: All Stakeholders*

<b>Obj.</b>	<b>Objective for Year 3</b>	<b>Definition of Success</b>	<b>Measurement of Success</b>
1	NEGC continues to participate in national work groups	The NEGC is actively represented on a national level by staff and NEGC constituents and contributes to the improvement and coordination of genetic services.	Meeting minutes and dissemination of information.
2	Catalog WG and AC member participation in national groups	Members participate in key groups across the sphere of agencies providing or impacting services for individuals with genetic conditions.	Member report out and disseminate information and documentation as applicable.
3	Link with affiliated programs (LEND and AUCD)	MOAs developed with participating programs identifying methods of collaboration	Meeting minutes, signed MOAs with other states
4	Represent genetics issues to wider healthcare system	Additional health care fields are educated about the needs of individuals living with genetic conditions.  Public Health Genetics and Genomics is integrated into other academic course work	Stakeholder participation on the Advisory Council, Members of the NEGC mailing list, # of publications in medical journals covering issues facing genetic services, cross-collaborative grants submitted with primary care providers.

The RC will utilize an innovative project program to accomplish unanticipated and innovative activities that emerge within the region.

*Led by: Innovative Projects Workgroup*

<b>Obj.</b>	<b>Objective for Year 3</b>	<b>Definition of Success</b>	<b>Measurement of Success</b>
1	Monitor innovative grant awardees	A common process is established and continuously improved for the review, selection and monitoring of awardees that is agreed to by all members of the review committee.	Meeting minutes.
2	Work with grantees to develop poster presentations	Poster presentations developed that represent and convey the spirit of the innovative projects program.	Poster presentation, review by management staff and Advisory Council.
3	Release and award grantees for 2009-10	Grant Cycle completed.	Report out during advisory, collaborative council and advisory council meetings. Release press coverage of field projects to local, regional and national audience
3	Confirm award amount and issue RFP for grant cycle 4	RFP issued.	Meeting minutes.

Priority Area 1: Multicenter Validation of Algorithms to Improve Communications of Positive Newborn Screening Results to the Medical Home

Led by: QUALITY ASSURANCE WORKING GROUP

<i>Obj.</i>	<i>Objective for Year 3</i>	<i>Definition of Success</i>	<i>Measurement of Success</i>
1	Continue collaborations, creation of indices and assessment of variability of testing across labs.	Assessment report completed documenting differences (and their drivers) across lab settings.	Report
2	Conduct data analysis using additional MSMS markers, expand to CAH screens.	<p>A table of additional (non-C3-related) cases identified in each participating region, showing the numbers of cases that fall into each of the three categories according to the pre-determined NENSP indices</p> <p>Development of detailed tables analogous to those created using New England data, for data from the collaborating laboratories, using the pre-determined NENSP indices.</p> <p>Table analogous to above, but for CAH disorders and out-of-range initial screens, derived from NENSP data alone.</p>	Tables produced.
3	Convene collaborative conference May 2010	Conference Held	Meeting minutes

Priority Area 2: To engage Regional, State, and Local stakeholders in a series of coordinated meetings to establish a Regional Charter for Best Practice and Data, and to produce data collection and registry manuals while continuing and expanding existing data sets used by the New England Newborn Screening Program in Massachusetts for feasibility tests, analyses, reports back to medical home and extracts for regional and national databases

*Led by: LONG TERM FOLLOW UP WORKING GROUP*

<b>Obj.</b>	<b>Objective for Year 3</b>	<b>Definition of Success</b>	<b>Measurement of Success</b>
1	Complete Regional Charter Agreement	Draft of Charter completed	LTFU Workgroup report that Draft presented to legal counsels.
2	Test of feasibility of data collection approach using NENSP LTFU variables	Limitations in data collection approach identified and solutions developed.	LTFU Workgroup Reports , presentations. publications.
3	Define the quality assurance minimum dataset	Dataset defined.	LTFU Workgroup Reports , presentations. publications.
4	Test of feasibility/census	Census information updated.	LTFU Workgroup Reports , presentations. publications.
5	Refine dataset variables per condition-specific needs	Variables reviewed at least annually and have support from Workgroups.	Meeting minutes
6	Participate in Interregional and NCC activities	Participation yields –import or export of products.	Meeting minutes.
7	Convene Regional Policy and HSR conference	Conference yields at least one interstate commitment to data sharing policy.	Conference Report

The RC will complete both quantitative and qualitative evaluations of processes and outcomes of all goals, activities and projects undertaken by the NEGC.

*Led by: Evaluation Staff*

<b>Obj.</b>	<b>Objective for Year 3</b>	<b>Definition of Success</b>	<b>Measurement of Success</b>
1	Gather data on program activities and outcomes and provide ongoing feedback to project staff on project progress	Management staff report evaluation support has been an effective aid in decision making and program improvement.	Annual review, Meeting minutes of review.
2	Conduct annual stakeholder survey	A majority of stakeholders participate in the survey process and provide recommendations for the project's improvement	Data collected, More than 50% of known stakeholders participate in the survey (documented by Survey Monkey), Stakeholder Survey report generated and published to website.
3	Complete semi-annual and annual reports which can be used by staff to improve project outcomes	Reports completed and utilized by staff to improve project outcomes and utilized by stakeholders to stay informed of project progress.	Meeting minutes affirming utilization of material, Stakeholder Survey report documenting majority agreement that the report is a useful resource for stakeholders.

## PROJECT CHALLENGES AND RECOMMENDATIONS

This section provides an overview of both project-wide and Working Group level issues identified by the evaluation team along with recommended next steps. Additionally, it provides an update on the status of activities as they relate to previous issues raised by the evaluation team. Status updates for each is defined as:

Not addressed: no substantive activities have been undertaken

In process: activities are under way to address the challenge

Improving: activities have led to substantial improvements in the challenge area

Addressed: challenge has been successfully met by project staff

### Year Two New Challenges and Recommendations

#### Many Stakeholders, Limited Funds

During Year Two, members of the collaborative began to grapple with the challenge of multiple members seeking grant applications to the same funding sources. Some of the issues encountered included: how to balance sometimes competing interests, when the NEGC (and its fiscal agent, UNH) should take a leadership vs. supporting role in a grant application, how to determine what is best for the region, and what is the identity of member agencies in terms of their partnership with the coalition and working towards the NEGC's mission vs. their own organizational mission.

#### Recommendation

In August of 2009, the collaborative council met and, in the process of discussing the above issues, developed the following protocol for handling future grant opportunities.

- Each organization participating on the collaborative develops a clear sense of its role respective of the NEGC and how the two can work together to mutually improve services in the region.
- Upon identifying a new grant opportunity, a potential grant applicant makes a determination as to whether the grant opportunity should involve the NEGC on some level (NEGC should be lead, participant, or supporter).
  - If an applicant determines that the NEGC should be involved, they contact Amy with a link to the grant, their intention to apply, a brief description of what they would like to do, and the potential role they see for the NEGC

- Once Amy receives a notice of a grant opportunity of interest, she will send out an invitation to collaborative council members to see if others want to apply as a lead applicant or as a potential participant.
- Within 24-48 hrs, CC members notify Amy of intent to apply and include information on: a brief description of what they would like to do (lead or participant), and the potential role for the NEGC
- Amy contacts interested applicants via email to let them know who is interested in applying as lead and who would like to participate.
- If multiple people are interested in leading the grant, they should talk within 24 hours after Amy's email notification to determine if a natural lead can be identified ( with leadership based on a range of factors: history of past funding, other partnerships which can be brought in, implications to current workgroup activity, what would make the application the most competitive and best represents the expertise of the region)
- If there is a difference in who should be the lead ...
  - Amy will seek additional information from the initiating grant project officer to determine if any additional details can guide a decision as to what grant application would be most successful. Information is shared with potential lead applicants.
  - Via phone conference or email vote (non-binding), collaborative members take a measurement of interest among its members and shares results with the applicants (e.g. 1 - Fully support an organization's application, 2 - Support with reservations (cite concerns), 3 - Would not support. Note that this process could be used for all NEGC grant applications, not just those where there is a conflict in lead applicant - PA
- The measurement of collaborative council interest will be utilized by project staff to determine appropriate language / use of support letters originating from the NEGC re: the current grant application

## Update on Challenges Identified to Date

### Common Conceptions of People, Roles, and Decision Making Processes

*Status: In process.*

During Year Two, substantive efforts were made to revise the NEGC website with information on project structure, major events and membership, increase email communications and updates, provide more accessible meetings, as well as monthly calls with workgroup chairs. Despite these endeavors, results from the Stakeholder Survey and the NEGC annual 2008 meeting continue to indicate a clear need for clarification on each of the project's structures, who is involved, what roles they have, how decisions are made, and how Working Groups are linked to other groups (both outside and inside the project).

### Recommendation

Continue to build on current efforts to renovate the web presence of the NEGEC, with a focus on making information accessible to both professionals and consumers. Develop an outreach plan for professional and consumer groups, specifying roles of each and how the NEGEC can aid them in their efforts. Develop a formal process for joining the coalition along with a set of expectations around their participation in the coalition.

### **Cross-Fertilization of Ideas, Resources**

*Status: Improving*

Several individuals from the stakeholder survey requested assistance in reaching out to other like-minded groups, both at the national level (e.g. learn about what other regions are doing with respect to long term follow-up) and locally (other useful resources at Dartmouth and UNH, as well as other affiliated institutions across the region).

### Recommendation

Project staff have sought connections with other regional collaboratives,. Recent discussions at the collaborative council level have further highlighted the need for better cross collaboration within the NEGEC. As a result, a new subgroup will be forming combining the resources and dedication of the quality improvement, medical home, and transition working groups.

### **Geographic Barriers to Meeting (was 'Travel Funds')**

*Status: Improving*

A problem impacting many Working Groups is difficulty bringing together stakeholders for collaborative tasks. In response, NEGEC has explored use of phone conferencing and web-based technologies and has encouraged working groups to do likewise. In addition, NEGEC has encouraged co-meeting scheduling to maximize participation across work groups. The NEGEC held a web conference for the collaborative council with success. However, it still is very helpful for groups to meet face to face on an occasional basis.

### Recommendation

Working Group leaders continue to be making good use of conference calls and technology to support their meetings, such as GoToMeeting.com and utilization of video conferencing technology through Webex. These resources continue to provide an effective means for members to conduct the work of the workgroup.

### **Quality Data Systems**

*Status: Improving*

The QI, Transitions, and LTFU Working Groups expressed a need for quality patient data systems. Such systems help researchers and providers to assess adherence to treatment protocols and assess treatment

outcomes. Regional data systems help to pool data to facilitate assessment of rare disorders. The budget for NEGC reflects the lack of emphasis by HRSA regarding their funding of data systems.

#### Recommendation

During the past year, project staff have actively sought new grant opportunities to aid in building quality data systems. Work around the QI initiative received \$75,000 in carry forward funds. Members of the LTFU workgroup have applied in Year Three for new funding to work with Maine's and Massachusetts data systems.

### **Tracking Progress of Work Groups**

*Status: Improving*

In Year One, an issue was raised by evaluation staff concerning the flow of information and timeliness of material / feedback provided. There continues to be improvements in communication as observed via monthly meetings, more timely responses to federal report requests, and openness in discussion during collaborative council meetings.

#### Recommendation

While there has been general improvement between workgroup chairs and NEGC staff, there continues to be variety in the level of information provided in workgroup minutes. At a minimum, all workgroups should include the following information in tracking their meeting events: meeting date, participants, major discussion points, barriers encountered and solutions identified (if any), next steps and person responsible. Minutes should be posted on the NEGC website no later than 2 weeks following a meeting.

### **Development of Logic Models and Performance Measures for Workgroups**

*Status: Improving*

Although evaluation staff sought to develop a series of additional logic models and measures with each of the Working Groups in Year One, it was decided by both project management and evaluation staff that such reporting went beyond the immediate needs of the project given current capacities, utility of the information, and changing dynamics of the federal level outcome measures. While improvements in information flow have improved in Year Two, workgroup chairs have agreed to an initial set of performance measures for their activities during Year Three.

#### Recommendation

Continue to refine and build on the current set of performance measures.

### **Medical Home Workgroup: Availability of Specialists**

*Status: Improving*

One of the challenges identified by the group is the scarcity of physicians with specialty training in genetics. More genetics doctors are leaving the field than are entering it. This trend could threaten the NEGC goal of improving patient access to quality care. Another challenge for Medical Home practice is that little case management information for genetics disorders has been published. If this information was more accessible, it is possible that PCPs could perform more elements of patient care. During Year Two, substantive efforts were made to educate both regional and national level stakeholders about the need for a medical home. In addition, the newly funded pilot project will help set the stage for documenting the importance and utility of medical home approaches in the region.

Recommendation.

Continue providing support to the medical home workgroup to enable further work in this area.

**Medical Home Workgroup: Lack of PCPs for Adults**

*Status: In process*

It appears that most adult patients with a genetic condition do not have a PCP. This problem may be related to a lack of health insurance. Anecdotal evidence in the region indicates that a relatively high percentage of the nonclinical young adult population does not have health insurance.

Recommendation.

Continue to support efforts of the Transitions Working Group and Medical Home Working Group to better understand the constraints to effective transition from child to adult care.

**Dissemination, Education and Marketing Workgroup - Patient Access to Genetics Information.**

*Status: In process*

Collaborative Council members suspect that genetics patients do not know how to access genetics information. It is also possible that low-income patients do not have access to information on the internet.

Recommendation.

The target audience for each product produced by the DEM Working Group should be clearly identified. Information about these audiences can then be used to facilitate dissemination. The Collaborative Council has concluded that a great deal of quality genetics information already exists. The DEM Working Group might consider focusing its limited resources on helping patients and providers to find the existing information to better ensure the quality of health care and outcomes for all patients with genetic disorders.

**APPENDIX A: NEGC ORGANIZATIONAL CHART**

# NEW ENGLAND REGIONAL COLLABORATIVE ORGANIZATIONAL CHART

## NEW ENGLAND REGIONAL COLLABORATIVE ADVISORY COMMITTEE

CT

RI

MA

NH

ME

VT

### REPRESENTATIVES FROM:

•Public Health

•Genetics Services

•Consumer Organizations

### REGIONAL COORDINATING CENTER (RCC AT UNH)

#### MANAGEMENT TEAM

- John Moeschler, MD, Project Co-Director
- Jan Nisbet, PhD, Project Co-Director
- Amy Schwartz, MPH, Project Manager
- Karen Smith, Project Coordinator
- Peter Antal, PhD, Project Evaluator

### COLLABORATIVE COUNCIL WORKING GROUP/LEADERS

<u>EDUCATION, DISSEMINATION, MARKETING</u>  Leah Burke, MD	<u>ACCESS TO SERVICES</u>			<u>FOLLOW-UP</u>  Anne Comeau, PhD	<u>LABORATORY QUALITY ASSURANCE</u>  Roger Eaton, PhD
	<u>LINKAGES TO MEDICAL HOME</u>  Carl Cooley, MD	<u>TRANSITION TO ADULT SERVICES</u>  Susan Waisbren, PhD	<u>QUALITY IMPROVEMENT</u>  John Moeschler, MD		

### STATE REPRESENTATION

CT

RI

MA

NH

ME

VT

## APPENDIX B: NEGC PRESENTATIONS LIST

### Sharing Work on Project Activities

Meet Your Neighbor: NEGC  
Genetic Alliance webinar  
May 2009  
Amy Schwartz

Poster Session: NEGC  
ACMG Meeting, Tampa, FL  
March 2009  
John Moeschler

Poster session: NEGC  
NCC/RC Meeting, Bethesda, MD  
January 2009  
John Moeschler & Amy Schwartz

Poster session:

- NEGC
- NEGC Work Groups
- Innovative Projects
- CSHN Survey Analysis Presentation – Bob McGrath

NEGC Annual Meeting  
Dec 2008

Long Term Follow up of Newborn Screening  
Conditions in New England ~ New Hampshire  
NBS Advisory Committee  
October 2008  
Anne Comeau

Long Term Follow up of Newborn Screening  
Conditions in New England ~ Rhode Island NBS  
Advisory Committee  
September 2008  
Anne Comeau

Long Term Follow up of Newborn Screening  
Conditions in New England ~ Maine NBS  
Advisory Committee  
September 2008

Anne Comeau

### Educating Students

Public Health and Genetics  
Rivier College and Nursing School, Nashua, NH  
March 2009  
Amy Schwartz

Class at UNH Graduate Program: Fundamentals  
of Public Health  
Fall 2008  
Amy Schwartz (co-faculty)

Innovative Project: Patients as Teachers  
Multiple presentations to medical school students  
2007-2009 (2 funding cycles)  
Mark Korson, Tufts University, project PI

Innovative Project: Nurse Educators Incorporate  
ANA Guidelines on Genetics  
Videotaped training module presentations, now  
available online  
2007-2008  
Susan Capasso, St. Vincent's Academy, project PI

### Training Professionals

Implementing AAP Developmental Screening  
Guidelines in the Primary Care Medical Home  
NH Pediatric Society  
April 2009  
Carl Cooley

DEM work group project: Family Health History  
Awareness  
Multiple presentations during pilot phase to health  
care community in NE, now available online  
2007-2009  
Meagan Krasner

Incorporating Genetics Into the Medical Home  
NEGC/NERGG Collaborative Session at annual  
meeting  
December 2008  
Carl Cooley  
Genetics presentation at NERGG annual meeting  
December 2008  
Leah Burke

The Primary Care Medical Home and the Care of  
Children with Metabolic Disorders  
New England Metabolic Program Consortium  
November 2008  
Carl Cooley

Newborn Screening Molecular Training Workshop  
November 18-24, 2008  
Anne Comeau

Newborn Screening and Genetic Testing  
Symposium  
November 3-6, 2008  
Anne Comeau

Keynote address  
International Conference for Adults and Children  
with PKU, Chicago, IL  
Aug 2008  
Susan Waisbren

Transition: Psychosocial Considerations  
(power point presentation, available on NEGC  
website)  
Susan Waisbren

Innovative Project: Sickle Cell Disease Life Skills  
Training to Improve Outcomes  
Multiple presentations to young adults in NE  
2007-2009  
Bill Kubicek, Next Step, project PI

## APPENDIX C: NEGC PUBLICATIONS LIST

### Year One

Spectrum of Medium Chain Acyl-CoA Dehydrogenase (MCAD) Deficiency detected by newborn screening  
Hsu H-W, Zytkovicz TH, Comeau, AM, Strauss AW, Marsden D, Shih VE, Grady GF and Eaton RB.  
*Pediatrics*, 2008;121:e1108-e1114

Newborn Screening Showing Decreasing Incidence of Cystic Fibrosis. Hale JE, Parad RB, Comeau, AM.  
*New England Journal of Medicine*, 2008, 358:9:973-974 (Correspondence)

Medical genetics diagnostic evaluation of the child with global developmental delay or intellectual disability.  
John Moeschler. *Current Opinion in Neurology*, 2008, 21:117-122

Expanded newborn screening: information and resources for the family. Susan Waisbren. *American Family Physician*, 2008, 77: 987-9

### Year Two

Parental tolerance of false-positive newborn screening results. Susan Waisbren. *Archive of Pediatric Adolescent Medicine*, 2008, 162: 870-6

Short-chain acyl-CoA dehydrogenase (SCAD) deficiency: an examination of the medical and the neurodevelopmental..Susan Waisbren. *Molecular Genetic Metabolism*, 2008, 95: 39-45

Stability of blood phenylalanine levels and IQ in children with PKU. Susan Waisbren. *Molecular Genetic Metabolism*, 2008, 95:17-20

Carlson D, McKeen E, Mitchell M, Torres B, Parad R, Comeau AM, O'Sullivan BP. Oropharyngeal flora in healthy infants: observations and implications for cystic fibrosis care. *Pediatric Pulmonology* 2009 May;44(5):497-502.

Comeau, A., & Levin, D. Population-based research within a public health system: two models for common rule compliance in the Massachusetts Newborn Screening Program In M. Bailey & T. Murray (Eds.), In: *Ethics and newborn genetics screening: New technologies, new challenges*. Baltimore, MD: Johns Hopkins Press.2009.

## **APPENDIX D. SUMMARY OF WORKING GROUP MILESTONES**

	<i>June 08</i>	<i>July 08</i>	<i>Aug 08</i>	<i>Sept 08</i>	<i>Oct 08</i>	<i>Nov 08</i>	<i>Dec 08</i>	<i>Jan 09</i>	<i>Feb 09</i>	<i>Mar 09</i>	<i>April 09</i>	<i>May 09</i>
Project Staff							Annual NEGC Meeting	Reapp. for federal funding.  Set agenda for the future: more consumer outreach, website changes, QI enhance.	Revised Innovative Project process as per Advisory Committee meeting	Developed NEGC brochure		
Innovative Projects	LOI due for 2008- 2009 projects	Proposal apps. due	Review process completed & awardees notified	2008-2009 Project start date							LOI due for 2009- 2010 apps	2008-2009 projects end
Advisory Committee							Annual Meeting held. Approved revisions in Innovative Project RFP and review process					Ratified new NEGC vision.

	<i>June 08</i>	<i>July 08</i>	<i>Aug 08</i>	<i>Sept 08</i>	<i>Oct 08</i>	<i>Nov 08</i>	<i>Dec 08</i>	<i>Jan 09</i>	<i>Feb 09</i>	<i>Mar 09</i>	<i>April 09</i>	<i>May 09</i>
Collab. Council											Drafted new NEGC vision.	
Evaluation Team	Yr 1 survey complete		Yr 1 survey results released	Year 1 annual report released				Mid-year update report released. National measures submitted.				Yr 2 survey started
Quality Improve.					Members agree to include check out sheet with patients					Draft protocol for clinician eval. for children with dev. delays		
Medical Home	Kick - Off meeting for the full medical home group.				Laid groundwrk for clinic part. in MH pilot.	Featured speaker at Metabolic Consort. annual meeting; introduced MH pilot	Dr. Cooley is featured speaker at NEGC/ NERGG Annual Mtg	Finished tool prototype and identified clinic sites.		Applied for care plan pilot with UMASS Med Center and Children's Hospital.		

	<i>June 08</i>	<i>July 08</i>	<i>Aug 08</i>	<i>Sept 08</i>	<i>Oct 08</i>	<i>Nov 08</i>	<i>Dec 08</i>	<i>Jan 09</i>	<i>Feb 09</i>	<i>Mar 09</i>	<i>April 09</i>	<i>May 09</i>
Transition	Teen Challenge – Boston  Conference for adults with PKU, Aug 16-17, Chicago;		Completed survey of adults with PKU		Developed protocol for psych. follow up that could be admin. by non-psychologists	Introduced focus on work group integration between QI, MH, and Trans		Started PKU support group	Submitted two LOIs for Innovative Projects –	Chair joined Transition Care Team through Harvard BWH/CHB Med-Peds;		
Diss. Education & Marketing	Defined focus and direction for the group's activities in 2008/2009			Intro. of special education chart to the group.				Draft survey developed.		NEGC staff compiled information about CEUs for special educators in NE	New timeline and objectives for the DEM workgroup	
Lab QA												Group review and approval of NENSP indices
Long-Term Follow-up						Hosted third Newborn Screening Molecular Training Workshop. Presented at 2008	Mass. supports newborn screening regulations that include		Report on LTFU of newborn screening conditions presented to Sec. Adv.			Regional Policy and HSR Conf.

	<i>June 08</i>	<i>July 08</i>	<i>Aug 08</i>	<i>Sept 08</i>	<i>Oct 08</i>	<i>Nov 08</i>	<i>Dec 08</i>	<i>Jan 09</i>	<i>Feb 09</i>	<i>Mar 09</i>	<i>April 09</i>	<i>May 09</i>
						Newborn Screening and Genetic Testing Symp.	LTFU.		Comm. on Heritable Disorders and Genetic Diseases in D.C.			

## APPENDIX E. WORKING GROUP MEETINGS

	<i>June 08</i>	<i>July 08</i>	<i>Aug 08</i>	<i>Sept 08</i>	<i>Oct 08</i>	<i>Nov 08</i>	<i>Dec 08</i>	<i>Jan 09</i>	<i>Feb 09</i>	<i>Mar 09</i>	<i>April 09</i>	<i>May 09</i>
Management				Mtg	Mtg	Mtg	Mtg	Mtg	Mtg	Mtg	Mtg	Mtg
Advisory Committee							Mtg					
Collaborative Council	Mtg			Mtg						Mtg		Mtg
Quality Improvement					Mtg		Mtg			Mtg		
Medical Home	Mtg				Mtg					Mtg		
Lab QA												Mtg
Dissemination, Education, & Marketing	Mtg			Mtg					Mtg			
Transition: Regional	Mtg	Mtg		Mtg		Mtg		Mtg	Mtg	Mtg		Mtg
Transition: National	Mtg	Mtg		Mtg	Mtg			Mtg	Mtg	Mtg	Mtg	Mtg
Long-Term Follow-Up: Full		Mtg	Mtg									Mtg.
LTFU: Hgb Workgroup		Mtg		Mtg				Mtg				
LTFU: CF Workgroup						Mtg						