

## **NEGC Collaborative Council Meeting**

September 26, 2008 10 AM to 2 PM

Present: John Moeschler, Carl Cooley, Leah Burke, Anne Comeau, Peter Antal (staff),  
Karen Smith (staff)

Absent: Susan Waisbren, Roger Eaton, Amy Schwartz (staff)

### **Welcome**

- Agenda and backup documentation available both online and in files ready to be added to CC binders

### **Basic Administrative Information**

- Carry-forward
  - Carry-forward request has been filed
- NCC/RC/PI quarterly call on Oct 30<sup>th</sup> from 9-10
  - Purpose of this call is to update the matrix, which describes activities in all regions
  - Group discussed state genetic plans and agreed with RCC approach

### **Policy review**

- Group discussed reimbursement for meetings & educational opportunities

### **Website**

- Group reviewed changes in the website
  - Calendar function
  - More options under About us
  - Collaborative Council working page has been developed for meeting materials
  - New link: AskTheGeneticist was discussed

### **Work Group Updates**

- Medical Home
  - Successful kick off meeting on June 18, 2008; will look at possible pilot project from specialist back to primary, instead of the other way around; possible development of care *planning* tool
  - Some of the challenges of project/field work were discussed
  - Hope to convene focus group of specialists at metabolic consortium annual meeting
- Dissemination, Education and Marketing
  - Energized by special education training chart created by Ann Dillon, will use to create survey Would like to go forward with general genetics education piece
  - Discussed [www.TRAIN.org](http://www.TRAIN.org) – a central resource for a host of public health related training opportunities both nationally and regionally
  - 2 areas to focus on: educating educators about genetics and how to get educators information they need about a specific child
- Quality Improvement
  - Patrick Miller's has been to every location of work group members
  - Would like some kind of data management tool operating in the background
  - Would compile data from whole group and feed back to them
  - Developed next steps for each location
    - Capacity for electronic records
    - Easy way to keep track of processes and outcomes that is not burdensome to workflow without much cost

- Implement in background data mgmt capacity. Group has been asked to write article on NE data by Mark Williams, will lead to publication
- Long Term Follow Up
  - Group realized last year that they needed an educational tool for the legal people from various states, in order to get to the goal of a legal agreement re: shared state data
  - State team meetings are happening
  - The group's goal is to have *complete* data
  - Hemoglobin group is taking off
  - Discussed difficulty holding meetings
    - Group discussed other ways to think of having meetings: conference calls, etc.
  - Psychosocial Follow Up
    - they will develop a list of variables, will take to other groups
  - Molecular training: using CF as a model

### **Innovative Small Projects**

- Group reviewed rank order of proposals after review process
- Group discussed changes to be made: score sheet is biggest change
- Group discussed ways to think about eligibility criteria
- Discussion of multi-year projects

### **NEGC/NERG meeting**

- Group discussed poster mock-up; developed plan to continue working on posters for annual meeting

### **End of Year Report and Stakeholder Survey**

- Council should read and provide final feedback.
- Stakeholder Survey – discussed possible changes for next year