

**National MS/MS Advisory Board
February 2, 2008**

Meeting Summary

Welcome and Introductions

Cindy opened the call welcoming the group and thanking everyone for their willingness to participate in the advisory board.

Discussion of Advisory Board Charge (Handout 1)

The Charge was approved with changes to the last bullet:

*Provide guidance for interaction and collaboration of Region 4 MS/MS working group with other **regional collaborative projects** and national entities (APHL, CDC, NCC, and NNSCRC)*

Overview of Project

The group suggested that the project title be changed from *Laboratory Quality Improvement of Newborn Screening by MS/MS* to **Laboratory Quality Improvement of MS/MS Newborn Screening**.

Project Participation

- Piero – participants went from 100 to 93 due to non participation (defined by no submission or contact for the period of at least a year despite reminders) all 7 were international participants. Their passwords were de-activated for data protections purposes.
- Currently there are 46 states participating. The group discussed barriers to securing the participation of every state. A few states had problems because of their contracts with private laboratories but this should be resolved soon possibly allowing them to participate.
- Training Course
The training is reserved for those who are actively involved in the project. It is limited to no more than 2 individuals per state per year.
- In response to requests made by participants, the following information/documents will be provided to the group:
 - A brief synopsis of the overall project
 - A list of past training participants
 - A copy of the training manual ([sent](#)).

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Supplement

Molecular Genetics and Metabolism will be publishing a supplement issue dedicated to the project. The workgroup will be listed as author with the names of all active participants listed in the appendix. Piero hopes to have the articles completed by [early summer 2008](#).

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Feedback and Suggestions for Improvement

Data Sharing

- The group discussed data sharing guidelines, IRB requirements, Human Subjects research, and HIPAA requirements, etc and how they apply to the data gathered by the project. The group will provide guidance on data sharing issues but does not have the expertise to approve guidelines or make legal decisions.
- Some have found that despite anonymization of data, an expedited IRB review is still required; in the past this has been handled differently by different participants; states may prefer to have control over this issue
- Mike thought that there was HIPAA exemptions or some reason that is OK because of the Trail of permissions (i.e. states have to have agreements, permissions) and it is for quality assurance purposes
- Steve Downs - As soon as the data is used for generalizable knowledge it is considered human subjects research and we are working with a vulnerable population (children)
- Piero suggested that input would be solicited from this group when requests are received
- Cindy suggested that we look at Priority 2 data sharing guidelines to get started
- Some feel that these decisions should be left up to states

Recruitment Opportunity

Harry Hannon volunteered to include recommended cut-off levels based on the data collected through the project in a publication that will reach over 350 labs around the world.

Other

Michelle asked the group to begin to discuss whether the project, which is now national and international in scope, but remains in Region has the support and structures necessary.

Next Meetings

Teleconference - June 2008

The date of the June meeting has not been determined. The group will be notified of the meeting date based on availability.

Face-to-face Meeting - November 2, 2008, San Antonio

The meeting in San Antonio will be held on the Sunday prior to the Newborn Screening Symposium. The advisory group will have a meeting in the morning. The whole group will meet in the afternoon.