

Public Health Infrastructure Cluster

Newborn Screening and Short
Term Follow Up Group

Goals and Objectives

- Identify Follow Up issues
- Collect and evaluate existing protocols
- Develop model protocols
- Address other newborn screening issues

Issue Identified

- **Model Practices for Short Term Follow Up**
 - **Progress:**
 - Identified a list of activities
 - Computerization, abnormal result reporting, follow up, closing cases, unsat specimen, Quality Assurance, etc.
 - Developed a list of actions relating to each activity
 - Data entry: manual or electronic
 - result notification: PCP, submitter, parent
 - confirmation data collection steps
 - Monitors: turnaround time
 - Compiled all activities/actions into a spread sheet
 - Individual programs identified their activities/actions
 - **Pending:**
 - A detailed comparison of activities/actions between state programs

Issue Identified

- **Repeat Testing Algorithms for Low Birthweights**
 - Progress:
 - Identified four major concerns
 - Low birth weight definition, Transfusions, ↑17-OHP, and TPN
 - Collected repeat testing algorithms from programs
 - Repeat based upon non-normal test results
 - Routine repeat testing guidelines
 - Collecting data regarding the effectiveness each algorithm
 - Cases identified or missed
 - percentage of babies with follow up
 - Pending:
 - Completion of model algorithms for low birth weight babies

Issue Identified

- **Develop Hospital Based Coordinator Responsibilities**
 - Progress
 - Identified programs with established coordinators
 - Consensus on a draft document
 - Forwarded to Advisory group for Review
 - Changes discussed and revisions made
 - Some programs have used document

Issue Identified

- **State Border Follow Up Issues**
 - Progress
 - Identified 3 issues
 - Born in one state; resident of another
 - Born in one state; transferred to another
 - Family moves from birth state to another
 - Consensus document drafted
 - Pending
 - Forward to Advisory group

Issue Identified

- **Inventory of Models/Practices to Identify and Inform PCP of Abnormal Results**
 - Progress
 - Dependent upon completion of previous activities

Issue Identified

- **Inventory of Model/Practices for Obtaining Confirmatory/Diagnostic Results**
 - Progress
 - Report form for MCAD has been drafted
 - Continue working on format/details of this report
 - Pending
 - Expand reports to other disorders

Issue Identified

- **Back Up Capabilities**

- Progress

- Representation on the NYMAC committee
 - Back up plan - include follow up
 - Group informed

Issue Identified

- **Connection with Long Term Follow Up Group**
 - Progress
 - One individual has membership on both groups (Bill Young (MI))

Issue Identified

- **Medical Home Website Review**
 - Progress
 - Request to check accuracy/completeness of specialists identified on website
 - Completed

STFU Summary

- Monthly conference calls
- Addressing multiple issues simultaneously
- Several issues are nearing completion
- Positive group dynamics