



Region 4 Priority 2 Workgroup
Telemeeting Agenda - Friday, December 19, 2008
1/866/489-0573; *4545164*

I. Welcome

II. Introductions and IBEM-IS Participation Updates – by State Roll Call

Please announce yourself. Your state, and, if applicable, the clinic you are representing and provide a brief update of where your center is in the IBEM-IS process (waiting for approval, finalizing IRB application, enrolling, consenting, etc.)

III. IBEM-IS Update

A. Building the Information System

1. Review set up of surveys for C3 elements
2. GA – 1 Interval Survey (Handout 1)
3. Galactosemia Enrollment Survey (Handout 2)
4. Galactosemia Interval Survey (Handout 3)

B. Implementation

1. Issues and Concerns
 - a. Assignment of UPIN numbers
 - b. Other?
2. SOPs for Implementation
 - a. IRB Renewals – must be submitted to MPH
Updated surveys posted to website
 - b. Invoicing for period ending 12/13/08
 1. Clinical State Lead Activities
 2. Case Enrollment

C. Clinical State Lead Activities

1. Updates on involving other sites within state

IV. Request from DocSite – integrating lab results into DocSite Applications

V. Family Functioning and Chronic Disease Project

VI. Comments / Announcements

- A. Next Meeting – January 16th 1 pm, CT / 2 pm ET
- B. Please enter/update your member information in the member registry
www.region4genetics.org
- C. Other

VII. Adjourn