



**Region 4 Priority 2 Workgroup**  
**Telemeeting Agenda - Friday, February 20, 2009**  
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. Galactosemia Interval Survey (Handout 1) (N. Leslie)
- B. Update on any new surveys

**IV. Engaging Department of Health**

- A. Using IBEM-IS Data
- B. Identify Department of Health contacts if state not already represented
- C. Implications for IRB applications

**V. Implementation**

- A. Enrollment
  - 1. Enrollment Report (Handout 2)
  - 2. IRB Enrollment records needed
- B. Clinical State Lead Activities
  - 1. Updates on involving other sites within state
  - 2. State Site Visit – opportunity for partnering
  - 3. Expectations for Priority 2 Workgroup Members
- C. Research Initiative ~ Family Functioning and Chronic Disease Project

**VI. Mountain States “care plans” meeting**

**VII. IBEM-IS & MEMSCIS “Expansion”**

**VII. Comments / Announcements**

- A. Presentations
- B. Next Meeting – March 20<sup>th</sup> 1 pm, CT / 2 pm ET
- C. Please enter/update your member information in the member registry  
[www.region4genetics.org](http://www.region4genetics.org)
- D. Rescheduling May meeting
- E. Other

**VIII. Adjourn**