



Priority 2 Workgroup Telemeeting
Agenda ~ Friday, March 19, 2010 @ 2 pm ET/1 pm CT
1/866/489-0573 at the prompt, enter *4545164*

- I. Welcome & Roll Call Berry and members

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.)

- II. IBEM-IS Update Berry/Hiner/Bentler

- A. Data collection report
(handout H.O. #1- data collected; H.O.#2 Consented)
- B. Recording parental alleles?
- C. Are we calling things the right names?
- D. Assigning patient numbers

- III. Update on national data collection efforts (H.O. # 3 – “80%” table) Berry
(Look at the very end for other elements to discuss)

- IV. Summary of surveys re data collection Hiner/Berry
Discussion

- V. Other Business/Adjourn:
- A. See you in Lansing April 15-16
 - B. Attached: Final version of summary paper to appear in Genetics in Medicine (Handout #4)