



**Region4**  
Genetics Collaborative

**Priority 2 Workgroup Telemeeting**  
Agenda ~ Friday, September 18, 2009 @ 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. Summary of parent discussion Groups (Handout #1) Wedepohl
  
- III. IBEM-IS Update Berry/Anderson/Hiner
  - A. Dialysis questions (finalize)
  - B. Discussion about “core elements”
  - C. Update on DocSite data retrieval
  - D. Data collection report (Handout #2)
  - E. NEED enrollment reports! (for IRBs) (Handout #3)
  - F. Next disorders
  
- IV. National and cross-regional collaboration Berry
  - A. NBSCTRN-NCC Data Collection update – Clinical Workgroup
  - B. Update on presentations – Poster for ICIEM, PPT for ASHG (Handout #4)
  - C. Update on publication – discussion of dataset
  - D. NEED info – any presentations re IBEM-IS June 08-May 09
  
- IV. Face-to-face: 11/20/09 – Update and discussion Hiner
  
- V. MEMSCIS update Hiner/Berry
  
- VI. Other Business/Adjourn Berry