

Priority 2 Workgroup Face to Face Meeting
Chicago Hyatt Rosemount
Agenda ~ Friday, November 20, 2009
9:00 am to 3:00 pm CT

9:00 AM – 9:10 AM	Welcome & Introductions <i>continental breakfast</i>	Berry/ Anderson
9:10 AM – 10:00 AM	National Initiatives on Long-term Follow-up A. Advisory Committee on Heritable Disorders In Newborns and Children (ACHDNC) B. LTFU Subcommittee – “Overarching Questions in LTFU and Treatment in Newborn Screening” – Roles, Responsibilities and Perspectives of families, primary care providers, specialists and state public health programs. C. Related National Issues and Activities – national data base	Berry/Jurek
10:00 AM – 11:00 AM	IBEM-IS Research Discussion <i>Handouts #1, #2, #3, #4, #5,#6</i> ~ with 10 minute break around 11 AM ~ A. Standard Operating Procedures 1. External requests for IBEM-IS data: individual/s, regional, national 2. Internal requests for data 3. Publications, abstracts, presentations 4. Authorship 5. Workgroup member responsibilities <i>Handouts #7, #8, #9</i> 6. Grant proposals 7. Other? B. Projects 1. Current 2. Proposed – brainstorming	Berry/Anderson
11:00 AM – 11:10 AM	BREAK	
11:10 AM – 1:00 PM	Creating Useful Data Reports A. What do you want to know? B. Exploring the DocSite Report Wizard <i>Handout - DocSite Quick Reference Guide</i>	Cameron Berry/Bentler

1:00 PM – 1:45 PM	<p>LUNCH <i>(optional) Refresher Training – Use of Docsite IBEM-IS platform</i> <i>Handout - DocSite Quick Reference Guide</i></p>	Berry/Bentler
1:45 PM – 2:45 PM	<p>Priority 2 Work Plan A. Disorder update <i>Handout # 10</i> B. Setting priorities New Surveys (dialysis, pregnancy, imaging, death, transplant, proposed next conditions, i.e., urea cycle, PKU) <i>Handout #11</i> C. Reviewing Data Entered into IBEM-IS <i>Handout - DocSite Quick Reference Guide</i> D. IBEM-IS Brochure <i>Draft brochure in packet</i> E. MEMSCIS <i>Handout #12</i></p>	Berry/Bentler
2:45 PM – 3:00 PM	Next Steps	Berry/Anderson