



Region 4 Genetics Collaborative Advisory Group

February 23, 2009

9 am CST/ 10 am EST

Call in number: 1/866/489-0573; *4545164*

Agenda

- I) Welcome and Introductions Cameron
Please provide your name, state and role in the R4 Collaborative

- II) Updates
 - A) National Connections Cameron/Berry/Rinaldo
 - 1) National Newborn Screening Translational Research Network Cameron
 - 2) Guidelines for becoming a National Project

 - B) Region 4 Cameron
 - 1) Region 4 Re-application
 - 2) Updates
 - (a) Base Funding
 - (1) Medical Home Education Deising/Griffin/Turner
 - (2) Care Coordination Arveson/Hiner/Wood
 - (3) Genetic Expertise Mendelsohn/Wedepohl
 - (4) Follow-up – EHDl Hoffman/Hiner
 - (5) Parent Coordinator Report Wedepohl
 - (b) Carry-forward activities
 - (1) Endocrine
 - (i) CAH & DSD Registry Hiner
 - (ii) CH 3-year follow-up Hiner
 - (iii) CAH 2nd tier testing Hiner
 - (iv) Access to Genetic Services Survey Wedepohl
 - (v) Family Functioning and Chronic Disease Hiner
 - (vi) State Site Visits Griffin/Cameron
 - (c) Priority Projects
 - (1) Priority 1 – NBS by MS/MS Rinaldo
 - (2) Priority 2 – IBEM-IS Anderson/Berry

 - III) Workgroup Products – EHDl State-to-State UNHS Follow-up Protocol Hoffman
*Action Item (Handout 1)

 - IV) Reminders Cameron
 - A) Please enter your contact information <http://Region4genetics.org>
 - B) Quarterly reports due 03/15/09 for quarter ending 02/28/09

 - V) Other news and issues Advisory Group