



CAH/DSD Registry Project
6/10/10 Telemeeting Agenda
1/866/489-0573; *4545164*

Meeting Goals:

- 1) Assess the status and needs of the partners to move forward
- 2) Identify new specialty partners – DSD, urologists and psychologists from each state
- 3) Develop plan to integrate essential partner expertise into workgroup
- 4) Reach consensus on categorization of DSDs
- 5) Self-identify IRB progress

- I. Welcome, Introductions by State Roll Call Sarafoglou
Please introduce yourself and give a brief update of where you are in the IRB application and approval process
- II. Plan to integrate essential partner expertise into workgroup Hiner
A. Update on teleconference held between Cynthia Cameron (Region 4 PI), Sally Hiner (Region 4 Project Coordinator) and psychologists David Sandberg (MI) and Walter Bockting (MN)
- III. State Assessment Update Workgroup
A. Identification of potential participating centers and number of children with CAH from each state.
B. Identification of DSD, Urology and Psychology Partners in Each State
- IV. DSD Data Elements Sarafoglou, Quigley, DiMeglio, Workgroup
A. Confirm categorization of DSDs
B. Identification of experts in DSD to oversee disease specific elements.
C. Begin assigning individuals from within the Region 4 and invited experts to develop DSD disease specific elements.
i. Turner's
ii. Klinefelter's
iii. 46,XX DSD No Androgen Effect
iv. 46,XX DSD Partial Androgen Effect
v. 46,XY DSD No Androgen Effect
vi. 46,XY DSD Partial Androgen Effect
vii. Other DSDs
- V. Topics for next telemeeting Sarafoglou/
Workgroup
July 8, 2010