

**Meeting Goals:**

- 1) Reach consensus for working with NBSTRN
- 2) Reach consensus on CAH Infancy through puberty data elements
- 3) Reach consensus on workgroup goals for remainder of fiscal year (and next fiscal year, if appropriate)

**Participating:**

Linda DiMeglio, Charmian Quigley, IN; Ming Chen, MI; Kiki Sarafoglou, Nancy Vanderburg, MN; Samantha Blum, OH; Pat Donohou, WI; Cynthia Cameron; Sally Hiner, R4.

**Working with NBSTRN – Discussion**

Cindy gave a brief overview of the ACMG Contract from NIH to develop data systems around NBS and Follow-up. Mike Watson talked with Cindy about the relationship between the work of Region 4 and the work of the NBSTRN. NBSTRN has a long term follow up workgroup. They are well funded. The NBSTRN also is developing CAH registry elements. Mike asked Cindy to explore moving our work from a regional project to the national level to reduce duplication. Kiki and Susan Rose participate in the national group. Cindy asked - given where we are in the process, what should our relationship with the NBSTRN be? Charmian noted that the urologists she and Linda met with believe this work should evolve at the national level.

Cindy clarified that regions were set up to develop projects, make them work, and then move them to the national level. She asked the group – what are the pros and cons of keeping regional or moving national? How would the region be involved at national level? Kiki reiterated she has shared the work of this group at the national level.

Cindy described the relationship between IBEM-IS and NBSTRN. By the time NBSTRN started, we had data elements developed and had data in the registry. We were able to transition this work to the national level when NBSTRN was funded. Charmian stated there is added value in developing at the national level. Linda cautioned that we don't want to lose ourselves in a national group. Kiki agreed with Linda's comment. Nancy said she thinks in terms of bringing national people to us. Cindy clarified that is not how the RCs are funded to do business. We do not bring the national to us; we expand regional projects to the national level. When this is ready to go national, it will be handed off. The question is when?

Cindy noted that NBSTRN is not ready to enter data. Region 4 is working toward entering data. Once this set of data elements is finalized we will have a survey in the database and can begin entering data as soon as IRB approval is received. Cindy will propose to Mike that R4 continue efforts toward data entry while working closely with NBSTRN. Cindy will see if NBSTRN can offer any support for data entry in Region 4 to move the data entry forward with Region 4 as a pilot.

**Continuing Review of Intake Survey Elements CAH Infancy through Puberty**

- A. Changes and corrections from November discussion – Kiki asked the group to review the highlighted rows. These reflect agreed upon changes from the November discussion. Comments and suggestions should be forwarded to Sally by December 31.
- B. The group resumed discussion of additional elements (starting with Q38 on Line 49). Decisions are noted on the attached document.

**Workgroup Goals and Planning for Remainder of Fiscal Year and beyond**

Tabled due to lack of time. This will be moved up on the agenda for the January meeting.

**Recruitment of Members**

Tabled due to lack of time.

**Announcements**

Next Meeting – Thursday, January 13<sup>th</sup>, 2011 @ 2 pm CT / 3 pm ET