

Endocrine Workgroup Meeting Regional Meeting – September 17, 2008

Participating: Linda Dimeglio, IN; Barb Lesko, IN; Kupper Wintergerst, KY; Ming Chen, MI; Ram Menon, MI; Kyriakie Sarafoglou, MN; Nancy Vanderburg, MN; Sally Hiner, Region 4 Genetics Collaborative Coordinator.

A. Review and finalize CAH survey registries: Excel tables of data elements for the DWSD registries were distributed. Questions were identified that will need to be addressed, as follows:

- Rules for clinician choosing to enter past lab work - must it all be under a different encounter date, or could past lab work be assigned multiple dates under one past encounter enrollment?
- Who is going to enter the data?
- How long does data entry take?
- What are options for training those who will be entering data in the information system? Can we establish a test site for self training?

Next steps:

- Sally will provide electronic copies of surveys to workgroup members
- Sally will check with other Regional Collaboratives to see if they have collected any treatment plan/data elements information for these disorders
- Workgroup members will forward comments they and other clinicians have about the data elements/changes to the surveys by October 31.

B. Possible Funding: Per Cindy Cameron, Region 4 has unspent funds from this year's grant. We will be seeking permission to carry-forward. Region 4 will need to submit a plan with specific activities to be supported by the funds carried forward. The group agreed they would like to have funding to support adding the CAH surveys to the Information System. Issues to be addressed were identified, as follows:

- Can we determine the number of CAH cases in each state to have a feel for data entry activity?
- Should both Classical and non-classical be added to the information system?

Next steps:

- Workgroup members will try to get a feel for numbers of cases as they talk with other clinicians in their state about the data elements and the registry. Estimates of the numbers of cases will be provided with data element feedback to Kiki Sarafoglou by 10/31/08

C. IRB: Several issues about the IRB process and resources necessary to comply were raised.

- For institutions where the IRBM-IS has already been reviewed and approved, an amendment can be submitted to add the disorders or sex development.
- For institutions working toward IRB approval for the IBEM-IS, disorders of sex development can be added now, so that the protocol can be submitted as a single application.
- There are templates for IRB documents available on the Region 4 website.

- Several of the workgroup members indicated resources are needed to make the IRB process happen within their institution. Suggestions included:
 - funding to offset the cost of IRB application preparation
 - Using carry-forward funds to support a Region 4 coordinator to facilitate the IRB process with all partner institutions.

Next steps:

- Nancy will determine which institutions have IRB approval for the IBEM-IS and which are in process. This information will be forwarded to the workgroup.

D. CAH and CH Algorithms for follow-up: This item was tabled. Kupper Wintergerst has agreed to lead the workgroup in addressing algorithms for follow-up. A Telemeeting will be scheduled to begin work on this issue. Linda Dimeglio and Kiki provided tools that will be shared with workgroup members.

Notes by Vanderburg and Hiner