



**CH 3-Year Follow-up Workgroup
Telemeeting Agenda
August 11th, 2011 ~ 10 am CT / 11 am ET
1/866/489-0573; *4545164*
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Notes from May workgroup meeting related to protocol and IRB.

KY state lab has a follow up data base for patients diagnosed with CH, as well as primary care provider names. Kupper is drafting a project protocol that can be used as a template for each state. KY DPH will require IRB review. KY will be able to tell which of the children are referred to 1 of the only 2 treating centers. KY DPH does track which centers were contacted. KY centers will send letters to the providers for the children not tracked by the centers.

KY List serve will send out a letter to patients to let them know that they will be receiving this survey. This will hopefully improve return rate and alleviate concerns about contacting patients and/or doctors about patients

Treating endocrinologists tend to be more active in the Peds Endos groups than in the AAP. Would it be easier to get the list for all endocrinologists in the state? Focus on the AAP in the instances when majority of kids are managed by primary care.

IL – confirmation of CH is done through Pediatric Endocrinologist. IL tracks diagnosing pediatric endocrinologist through the NBS program. IL also tries to track if the CH has been found to be transient. IL has an administrative clause in their law for NBS that includes long-term follow-up, which should cover asking the physicians to provide information back.

OH – NBS follows up with primary care and keeps the case open until diagnosis is made. Does not ask for referring endocrinologist information. Do have primary care provider name. If the state lab has a list of patients, can that list be sent to the PCPs and Endocrinologists? Abnormal call out goes to PCP, PCP decides who to send the child to. (Chaudhari)

WI – no need to go to DPH, all information is at the state lab. STFU is done in the WI Lab which is not part of the health department. Reviewed this project with the pediatric endocrinologists group. They are really supportive and willing to provide any data that we ask for. Will go through IRB; probably can be exempted because data collected will be de-identified, even though at project initiation, each state will need to know the identity of the patient. (Hoffman)



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MN – do follow-up for one year. Track PCP and identify specialist. 7% of kids don't ever see a specialist. Have a few pediatric Endocrinologists who don't believe CH kids need to be followed by endocrinologists – view it as a pediatric disorder. There are 25 pediatric endocrinologists in MN. Started LTFU in March of 2008, so may have issues with 2007 data. Nancy will see what is available. Will probably go through IRB. Will submit as QA.

MI – Ram deferred to Bill Young who is not on the call. Does not anticipate challenges.

IN – IDPH does not do follow-up data. Only collect PCP at time of abnormal NBS identification. Have very few pediatric endocrinology centers. Erica is the coordinator, so has pretty good idea of who babies are and who sees them. (Eugester)