



**Region 4 EHDI Follow-up Workgroup  
Telemeeting Agenda - Thursday, December 18, 2008  
1/866/489-0573; \*4545164\***

Participating: Gary Hoffman, WI (lead); Kelly Daniel, KY; Michelle Garcia MI; Kirsten Coverstone, Barb Dalbec, Yaoli Li, MN; Reena Kothari, OH; Ravi Shah, WI.

I. EHDI Registry

Minnesota State Department of Health is not able to fund development of the Registry. We do have a nearly final product. Ravi Shah worked to finalize on a very short time frame. How would the group like to proceed? Action: This needs to be a discussion item for a future meeting.

II. EHDI Priorities & Genetic Issues

- A. A proposed goal, based on issues and priorities identified by the workgroup to date with a connection to heritable disorders identified through EHDI in Region 4 was developed by Ohio workgroup members (Kothari, Nottingham and Starr) and disseminated prior to the meeting, as follows:

**Increase Access to Genetics Services for Children with Hearing Loss**

1. Discussion:

- Can this group look at the diagnosed children in each state and determine if, these children are referred for genetics risk assessment, counseling, etc, at all?
- If so, of those that are referred and receive genetic counseling, what is the breakdown of syndromic vs. non-syndromic losses, age of identification, etc?
- From this, we can formulate how to better educate families, professionals and others in early intervention about genetics and hearing loss, etc.
- Is anyone collecting this data? Would it be useful? Could inform the effort to refer and connect; use the information to improve referral.

2. Proposed workgroup activity:

- Determine the extent of the problem
  - a. Who is collecting this information?
  - b. Who might be collecting this information?
  - c. Who would we ask?
  - d. What would be ask?
- Develop a core set of questions with target group specific questions
  - a. Suggested question
    - i. How many involved in your birth defects database have hearing loss or were identified with hearing loss?
- Suggested target informant groups
  - a. Audiologists
  - b. Early Interventionists
  - c. Region 4 State Leads
- Develop a survey
- **Action needed:** Email suggestions to Reena Kothari (Who to ask, what to ask)

B. Ideas for Region 4 Priorities

Reena drafted a list of activities/products/strategies to address the Region 4 Priorities. Group agreed many of these are achievable. Need input from the broader group.

**Action needed:** Indicate strategies/activities/products you are interested in working on. Indicate if willing to take a lead role.

III. EHDI Products, Activities:

A. Border Baby Protocol

Need the group to act on prior to going before the R4 Advisor Group as a recommended practice.

**Action Needed: Review prior to next meeting in preparation for vote**

B. Genetics & Hearing Loss Brochure

Is the group interested in adapting this tool for Regional use? If so, how would we disseminate? Where?

Decision: Include as a proposed strategy/activity/product

C. Form for collecting information on Risk Factors

The group would like more information from Joan Erhardt about her idea. The group did discuss if and how Risk Factor information currently is collected.

- WI has added 4 risk factors to the NBS hearing screening card
- MN – some risk factors are collected on the birth certificate

The group would like more information on how the information would be used. Also, how would the form be implemented.

Decision: Table until Joan can address.

IV. Member Directory

Members are reminded to enter their contact information into the online R4 Member Directory ([www.region4genetics.org](http://www.region4genetics.org))

V. Next Meeting

January 15, 2009

11 am CT / 12 pm ET

Notes by Hiner