



CH- 3 Year Follow-up Workgroup Meeting Agenda

Wednesday, April 14th, 2010

3:30 – 5:30 pm

The Henry Center ~ Lansing, MI

- I. **Welcome & Introductions** **Wintergerst**

- II. **Workgroup Logic Model** **Wintergerst/Hiner**
 - Handout 1*
 - A. **Short- and Long- term Follow- up**
 - 1. **Retrospective model**
 - 2. **Prospective model**
 - B. **Management Protocol Development**
 - C. **Provider Education Development***

- III. **Data & Activities**
 - A. **Challenges with CH NBS Interpretation** **Wintergerst**
 - 1. **Congenital Hypothyroidism**
 - 2. **Hypothyroxinemia of Prematurity**
 - 3. **Delayed Thyrotropin Elevations**
 - 4. **Sick Euthyroid Syndrome**
 - 5. **Transient Hypothyroidism**

 - B. **National/International – Published CH Data Summary**
Handout 2

 - C. **Region 4 Project – MI 3- Year Pilot** **Young**
Handout 3
Handout 4

 - D. **Region 4 Survey** **Hiner**
Handout 5

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IV. Selecting Our Destination
Where can the workgroup go from here?
Resources

- A. State Lab
- B. Pediatric Endocrinology Referral Centers
- C. Community Pediatricians

IV. Data to Help Us Chart Our Course

- A. What data are needed?
 - 1. Initial State CH Data
 - 2. Demographics
 - 3. Term/preterm/gestational age/BW
 - 4. NBS Results
- B. Reported State Follow-up
 - 1. State by State
 - 2. Time to report
- C. Provider Data
- D. Where are the data?
- E. How can we Access the Data

Group

V. Next steps

- A. Establishing State Leads
- B. Formalizing Project
- C. Developing Protocol
- D. Navigating IRB Approval
- E. Getting a Move On

Group

Handout Quick Reference

Handout 1 - Logic Model

Handout 2 - AAP Update of Newborn Screening and Therapy for Congenital Hypothyroidism

Handout 3 - Ch 3-Year Follow-up slides

Handout 4 - MI Pilot Project CH Survey

Handout 5 - Region 4 CH Workgroup Survey highlights