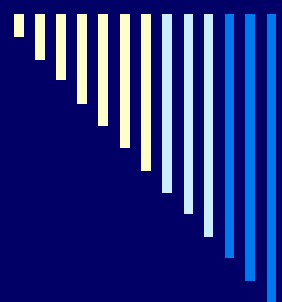


# Regional Evaluation of Newborn Screening for Detection of Endocrine Disorders

A Review of the Proposal

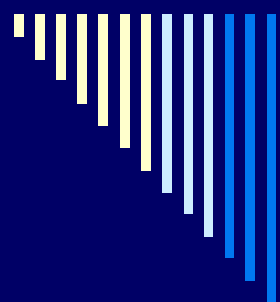
---



---

Conduct an epidemiological  
evaluation of CH and CAH in at  
least four States

---



# Four Purposes

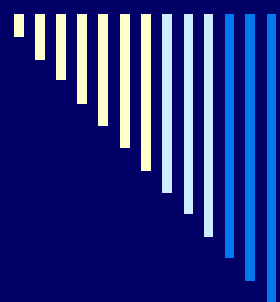
1. Determine case definitions used in each State
2. Describe current screening, follow-up and diagnostic methods
3. Evaluate and compare false positive and negative rates, PPV and detection rates
4. Provide consensus recommendations for improving detection rates and reducing false positive and negative rates in the region



---

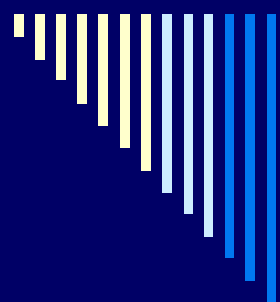
# Needs related to newborn screening for CH and CAH

1. Lack of case Definition for CH and CAH
  2. NICU Detection of CH and CAH
  3. Change in CAH test kit
-



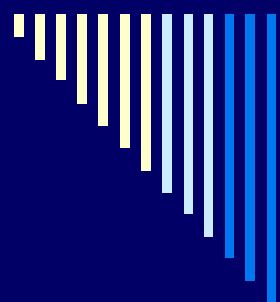
## Methodology: Activities

- Examine the spectrum of screening methods used by the participating laboratories; the cutoff values set by the labs and when there are differences in cutoff values, the reason for them; and if and how the variance in cutoffs impact on false-positive/false-negative rates.



## Methodology: Activities (Cont.)

- As a subset, evaluation of CH and CAH screening procedures and outcomes for premature and small for gestational age infants



## Methodology: Activities

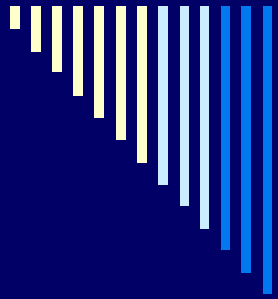
- Examine the false-positive and false-negative rates, positive predictive values and detection rates for each screening method among participating laboratories and identify approaches to improve these screening metrics.



---

# Participants

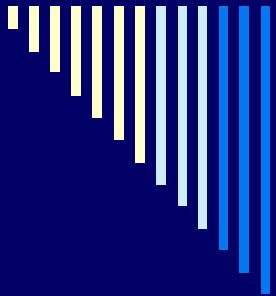
- Working Group: Short Term Follow-up serves as steering committee.
  - Dr. Cynthia Cameron provides administrative oversight
  - Michigan Department of Community Health serves as host site
  - Dr. William Young serves as project lead
  - Charles Mundt serves as project epidemiologist/coordinator.
-



---

According to the Proposal: the PEC will use Michigan as the test case and:

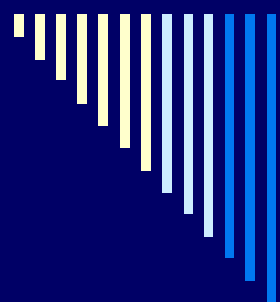
- Develop a process for identifying and obtaining the required data sets;
  - Establish a database and framework for data evaluation;
  - Conduct the required epidemiological analyses; and
  - Issue a state-specific summary report.
-



---

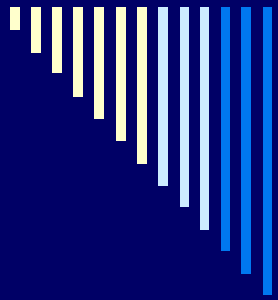
## After orientation and trial using Michigan data the PEC will:

- Schedule telephone interviews and/or in-person site visits in other states:
    - What are the methods and follow-up issues;
    - The feasibility and methods for procuring endocrine laboratory data will be discussed and arranged.
    - Upon receipt of data from other states, the PEC will analyze each state's data according to the established protocol
-

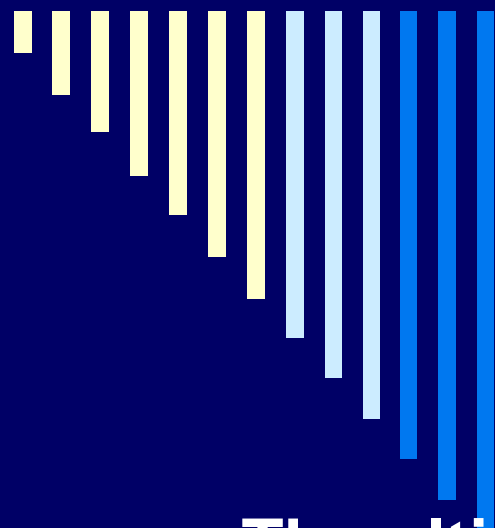


# Identify Experts

- The Steering committee will identify experts who will attend a consensus meeting. At the meeting the experts will discuss and provide input on the recommendations before they are finalized.



The project results will be disseminated.



## Project Outcome Measures:

**The ultimate outcome measure will be the identification of the most effective newborn screening strategies for CH and CAH within the region.**

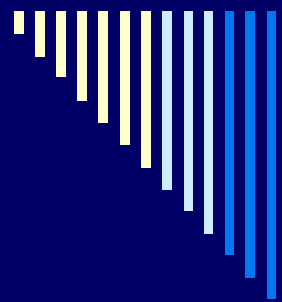
---



---

## Outcome:

- An additional quantitative measure of success will be the completion of an individual epidemiological profile of CH and CAH screening for each participating state.
-



## Outcome: (Qualitative)

- Level of Participation by Region 4 states and their satisfaction with the process used to establish consensus given existing differences in current approaches to CH and CAH screening.