Communicating Incidental Findings of SCT on the Newborn Screen

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Critical Gaps & Future Directions

This study shows that as many as 1.5% of babies born in the United States have SCT. Based on previous studies, there are no standardized methods or protocols for alerting families or healthcare providers to this information, educating them about the potential health outcomes that might be associated with the condition, or counseling them about the impact that this might have on the family’s future reproductive choices. By including educational materials and providing genetic counseling at the same time that families are given positive SCT results, the occurrence and public health burden of SCD might be reduced.

- The ASHG recommends additional research for assessing the utility of disclosing carrier results generated from NBS for reproductive decision making and cascade testing, as well as the impacts on systems of care and resources in the context of engagement with relevant stakeholders.
Community Needs Assessment

Focus Groups and Semi-Structured Interviews

• 29 participants
• Ages 20-40
• Self-identified as African American or West African
• All parents
Focus Group Findings

Why is this important for parents to know?

• Knowledge is power
• Reproductive risk
• Health burden of SCD
• Prior awareness
Focus Group Findings

What qualities of the notification are valuable?

• Knowledge base
• Personal relationship
• Provision of support/resources
• Timeliness
Major Conclusions

• Parents in communities most affected by sickle cell trait want to be made aware of their newborn’s trait result

• Carrier result notifications should be:
  – Multi-faceted
  – Facilitated by an individual knowledgeable on hemoglobinopathies
SCT Notification Changes

- MDH Newborn Screening has developed a multi-faceted notification process
  - Letter/mailing directly to parents when SCT is identified
  - Phone number of SCT educator will be provided to answer additional questions
  - PCP (listed on NBS cards) will be contacted and directly sent results with resources
  - Began June 2015
- Continue outreach to increase awareness of sickle cell trait and disease
1. Report is received by clinic listed on the newborn screening specimen card
2. Infant is registered and seen at clinic
3. Provider discusses result with family
4. Provider confirms the result through hemoglobin electrophoresis
Analyzing the process prior to changes:
Returned checklists from providers:

144

67%
Infants whose providers received newborn screen report: 81
Infants that were confirmed patients in listed clinic:
Infants whose results were reviewed with family:

56

26%
Infants that had confirmatory testing:

48

22%
Infants that had all actions completed:
Notification Process

1. Report is received by clinic listed on the newborn screening specimen card
2. Infant is registered and seen at clinic
3. Provider discusses result with family
4. Provider confirms the result through hemoglobin electrophoresis
Our process now:
Next Steps…

• Focus group of parents receiving notification
  - Reaffirmed current, active method to notification
  - Provided suggestions for increased parental engagement and understanding

• Expansion to other hemoglobin traits
• More outreach and increased awareness
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Questions???

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