

Expanded Newborn Screening: *If we offer it, will they come?*

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Collaborators

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Project Overview

This project will use a *Town Hall Meeting* format to inform the public about genetic counseling, genetic tests and services, and newborn screening.

It will also collect information about the public's awareness of and concerns with these issues to improve future education projects.

Priority Area Addressed

Heartland genetics & Newborn Screening Collaborative

Goal 2:

Promote genetics education regarding resources, clinical and laboratory services (availability, access, indications, limitations and benefit), genetic testing, teratogen services and genomics. Facilitate integration of genetics education into the curriculum of schools (primary and secondary), vocational schools, colleges and schools of health, such as medical schools, residency programs, nursing schools, and allied health.

Background

- **Newborn screening began in the 1960s, but states vary widely on test panels.**
- **Genetic Counseling has been around since the mid 1970s.**
- **With the Human Genome Project, genetics issues have captured national attention.**
 - **Genetic Disorders & Family Planning**
 - **Cloning & Genetically Altered Crops**
 - **Stem Cell Research & Gene Therapy**
- **The primary information available to the lay public is from non-scientific sources.**

Specific Aims

This project proposes to hold Town Hall-style meetings in Arkansas and Oklahoma to meet the following goals:

- 1. Provide information about the potential benefits of implementing expanded newborn screening to young adults, likely to use these services**
- 2. Identify misunderstandings, areas of concern and barriers to the support and implementation of expanded newborn screening**
- 3. Provide information about genetic testing, genetic counseling and related services that are available within the state**
- 4. Identify misunderstandings, areas of concern, and barriers preventing the full utilization of available genetic services**

Methods

Target Population: College students & Young Adults

Procedure: Eight Town Hall Meetings

2 Oklahoma City, OK

2 Tulsa, OK

2 Little Rock, AR

2 Fayetteville, AR

Data Collection: After presentation by regional experts (Mulvihill in Oklahoma & Kahler in Arkansas) and health department representatives, audience participants will be asked to submit questions on the issues covered. These questions will be recorded and used to assess audience knowledge level and concerns.

Progress to Date...



Challenges

Roll out of Expanded NBS in OK and AR

Loss of Collaborator in AR (Blaine goes to Med School)

Budget Cycle

Progress to Date...

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Needs

Additional Collaborators

Meeting sites in Tulsa and Fayetteville