

**PUBLIC HEALTH
GENOMICS CAPSTONE
PROJECT**

FUNDED BY HEARTLAND REGIONAL
GENETICS COLLABORATIVE
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**PUBLIC HEALTH GENOMICS
CERTIFICATE PROGRAM**

Program Objectives

- Provide training in public health genetics/genomics;
- Make aware of the contribution of science in the disease process;
- Educate on the importance of translating genomic research findings into appropriate interventions and prevention strategies;
- Familiarize professionals with the challenges including issues of privacy and confidentiality;




PROGRAM OBJECTIVES (Cont'd.)

- Introduce opportunities within the field of public health genomics; and
- Provide sufficient knowledge to negotiate the field, recognize the limits of their expertise, make appropriate referrals, and identify available resources.



PROGRAM MODULES


- Introduction to Public Health Genetics/Genomics;
- Genetic/Genomic Research: Issues and Informatics;
- Genetic Testing and Screening;
- Public Health Genomics: Practice and Policy; and
- Capstone Project.



CAPSTONE PROJECT

Develops a project that is public health/genomics related that:

- Integrates the material covered in the program; and
- Connects the student to a workplace setting that can be of use to them currently or in career opportunities.



CAPSTONE PROJECT (Cont'd.)

Purpose

- To determine knowledge and attitudes of the public about their awareness of newborn screening;
- To determine attitudes of blood spot storage to determine the best way to let parents know their options of storing their child's blood and using it for research; and
- To document parent feedback regarding the issue and develop policies and procedures on the methodology of the blood storage and research.



CAPSTONE PROJECT (Cont'd.)

Methodology

- Focus Groups around the state
- Survey

Questions for the focus groups and surveys were taken from the State of Michigan's Biotrust Initiative. Some questions were modified for Missouri.



FOCUS GROUPS

Group Discussion

- What have your experiences been with newborn screening (heel prick)?
- What are your thoughts about storing the blood for five years to use for medical research if all personal information is removed?
- What types of research using dried blood spots do you feel would be acceptable?
- How should consent to use the blood spot sample for research be obtained?
- Now that you have heard this information, what would you tell your friends?



FOCUS GROUPS (Cont'd.)

- Four focus groups have been held.
- Areas covered - central, east, and southeast regions of Missouri.
- Attempting to cover the west and northwest regions.
- Results have not been tabulated. However, preliminary results show that individuals were not aware of newborn screening, but were very positive about using the spots for anonymous research.



SURVEYS

- Surveys were given to the focus group participants.
- Similar questions were asked and in addition, some demographic information were included.
- Preliminary findings indicate that the participants were not aware of newborn screening, but were willing to allow the state to store the blood and use for anonymous research.



SURVEYS (Cont'd.)

Surveys will also be sent to a random sample of parents:

- with normal newborn screening results
- with abnormal newborn screening results



LESSONS LEARNED

- A multiple prong approach to education is needed.
- Clear explanations and education of individuals are essential.
- Individuals are receptive if they truly understand the situation.