

*Monday, February 23, 3:30PM-5:00PM
Concurrent Breakout Session B*

Using Residual Blood Spots from Newborn Screening Programs for Public Health Research

Moderator: Richard Olney, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA

Texas's Experience to Retain, Store, and Use Newborn Blood Spots

Mark A. Canfield and **Peter H. Langlois**, Birth Defects Epidemiology and Surveillance Branch, Texas Department of State Health Services, Austin, TX

Michigan's Neonatal Blood Spot BioTrust: Progress and Challenges

Janice Bach, State Genetics Coordinator and Manager; Genomics and Genetic Disorders Section, Michigan Department of Community Health, Lansing, MI

North Carolina's Experience with Acquisition of Newborn Blood Spots for Local Research Applications

Robert (Bob) Meyer, North Carolina Birth Defects Monitoring Program, Raleigh, NC

State health departments, through newborn screening programs, receive blood spots dried on filter paper that have been collected from nearly all children born in the United States. Collection of blood is now mandated by all states to identify newborns with various disorders so that interventions to decrease morbidity, mortality, and disability can be instituted rapidly. To ensure sufficient specimens are available if re-analysis is needed, more blood is collected than is routinely used to test for the panel of disorders established for each state. This session will focus on the storage and use of residual blood spots for public health research in the United States. The experiences from three states will be highlighted.

In Texas, there are currently 400,000 live births annually and the state has a large birth defects surveillance system. When the Texas Birth Defects Registry started in 1994, there was a vision of having a newborn screening blood spot linked to every child born with a birth defect in Texas, and in 2002 the state began retaining all blood spots from the Texas Newborn Screening Program. Texas now has millions of blood spots that can be linked to all live births, cases of birth defects, and other childhood disorders. Topics for the Texas presentation will include the successes and challenges in developing this initiative, as well as examples of ongoing and planned research using these blood spots for birth defects research.

Over the past several years, the Michigan Department of Community Health has been working to establish a neonatal biobank of dried blood spots in order to better preserve the samples and increase availability for public health and medical research. An overview of the progress and challenges, especially in relation to public engagement and acceptance, will be presented.

The final presentation of the panel will discuss North Carolina's experience with acquisition of newborn blood spots for selected local research applications. The presentation will describe: 1) linkage of newborn metabolic screening data with other public health data systems such as vital statistics and birth defects surveillance data; 2) use of the linked data to facilitate subject tracing in epidemiologic studies; 3) obtaining informed consent for the use of identifiable specimens for the ongoing National Birth Defects Prevention Study; and 4) future applications, including creation of an anonymous case-control blood spot bank for use in pilot and exploratory studies of candidate genes or occupational/environmental markers of exposure associated with the risk for selected birth defects and pediatric tumors.