Tuesday, February 24, 3:30PM-5:00PM
Concurrent Breakout Session D

Research Implications of Defect Classification and Coding Practices
Moderator: Lisa Marengo, Birth Defects Epidemiology & Surveillance Branch, Texas Department of State Health Services, Austin, TX

Angela Scheuerle, Tesserae Genetics, Dallas, Texas
Robert Meyer, North Carolina Division of Public Health, Raleigh, NC
Marcia Feldkamp, University of Utah, Salt Lake City, UT

Birth defect surveillance data go through a lot of steps to appear in analytical summaries. At each step of the way, a decision of some sort has to be made about how the data are handled. Do we collect X and Y or just X? Or just Y? Or maybe just X under some conditions? When we collect X, under some conditions, do we consider it to be useful only in a certain context? if it is found in this way, let's use one code, and we'll use another code when the context is different. It is impossible to program a computer (I think) to do this thought process because there are too many nuances. Adding humans into the mix will simplify some things and frustrate others: 5 geneticists in a room will give you 7 or 8 opinions about how to collect, abstract and code a defect. Each of these factors impacts how the data are presented to the people who then used those data in studies. Dr. Scheuerle will walk through some of these steps and considerations for all of them.

Dr. Meyer will then illustrate how the use of different coding systems (ICD-9-CM and CDC/BPA) can effect the prevalence estimates for various types of birth defects, and how measures of association such as odds ratios can also be affected. The presentation will also address issues regarding comparison and interpretation of prevalence data and risk ratios derived from programs using different coding systems.

As an extension from the other presentations, Dr. Feldkamp will focus on the epidemiologic study of risk factors and how decisions made at the surveillance step impact research capacity. Each decision within the surveillance system and how cases are classified will affect the potential to identify risk factors. This talk will present the challenges that these decisions create using secundum atrial septal defects as an illustration.