

Monday, February 28, 1:30PM-3:00PM
Concurrent Breakout Session A

Improving Birth Defects Data Quality: Accuracy Standards, Improving Accuracy and Completeness using Health Information Exchange, and Laboratory Reporting of Chromosomal Results

Moderator: Deborah Fox, New York State Congenital Malformations Registry, Troy, NY

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Patricia Steen, New York State Congenital Malformations Registry, Troy, NY

Marcia Feldkamp, Utah Birth Defect Network, Salt Lake City, UT

In 2004, the NBDPN released the *Guidelines for Conducting Birth Defects Surveillance*, an important first step to improve the quality of state birth defects surveillance data. The *Surveillance Guidelines* provided a “blue print” for states on what a birth defects surveillance program “should” do. To further improve birth defects data quality, a Standards Workgroup was formed to research and develop a “model” for setting minimal standards, or “musts”, for birth defects surveillance. Workgroup recommendations will serve as the gold standard for state birth defects surveillance programs. The hope is that the resulting document will be used to guide program development in order to assure the same level of high quality birth defects data across all state programs. When standards are attained for each state with a birth defect surveillance program, it will be possible to combine de-identified state data into a national data set, the analysis of which will greatly improve the understanding of birth defects trends and etiology, and move us towards our ultimate goal of prevention.

In this breakout session, Standards Workgroup member Deborah Fox will describe progress to develop accuracy standards. Patricia Steen will describe usefulness of access to remote electronic medical records to assure accurate reporting. The Utah Birth Defect Network has been able to obtain laboratory results electronically. Marcia Feldkamp will describe how they are making good use of the chromosomal results obtained from laboratories.