

# Surveillance Authority and Methodology

## Surveillance Authority

In 1997, the DOH received funding to operate and manage a statewide birth defects registry in response to the public's ongoing concern about birth defects and environmental hazards. On July 4th 1999, congenital malformations were added to Florida's List of Reportable Diseases/Conditions (Florida Statutes 381.0031; Rule 64D-3.035, Florida Administrative Code), establishing the legal authority to conduct birth defects surveillance. The mission of the FBDR is to provide complete, quality data that can be utilized by health providers and health policy makers.

## Surveillance Methodology

The FBDR is a comprehensive, unduplicated inventory of birth defect cases in Florida. The registry is constructed using a hierarchical, stepwise linking algorithm to link records from administrative data sources to birth and death certificates. Although the case ascertainment data sources have changed over time due to availability or funding restrictions for some data sets, or the addition of new, reliable data sets, the FBDR has leveraged the following data sources:

### Current Sources:

- (1) Agency for Health Care Administration inpatient (1998-current), outpatient (1998-current), and emergency department (2010-current) hospital discharge records
- (2) Florida Bureau of Vital Statistics infant death (2009-current) records

### Previous Sources:

- (1) Children's Medical Services (CMS) Regional Perinatal Intensive Care Center (RPICC) data (1998-2008)
- (2) Early Steps (ES) program data (1998-2008), and Minimum Data Set (MDS; encounter-level, service-related) records (1998-2007)

Once linked to the birth certificate, these sources are then scanned for International Classification of Diseases, 9th Edition, Clinical Modification (ICD-9-CM) or ICD-10-CM codes indicative of birth defects. Complete, accurate, and timely data are the cornerstones of an effective surveillance program; thus, the quality of the data sources and the linking methodology are imperative. Over the years, the FBDR has conducted several evaluations on the completeness, accuracy, and timeliness of the registry in order to quantify the under-ascertainment of birth defect cases resulting from the anticipated loss of the Children's Medical Services (CMS) specialty care data sources: ES data, RPICC data, and MDS.

Using data from the 1998 to 2007 FBDR, one study showed an overall 5% reduction in completeness of ascertainment with the loss of all three CMS sources, however, the impact of their loss varied by defect. Moreover, subsequent evaluations examined the utility of adding infant death certificate data to the FBDR, and one evaluated the combined contribution effect of the added infant death certificates and ED data. All these studies emphasized the importance of understanding the relative contribution of various data sources, not only to overall case ascertainment, but also to the disproportionate contribution across defects and population subgroups. Based on these and other studies, changes were implemented to improve the functionality of the FBDR. The surveillance methodology of the FBDR continues to be evaluated

in order to provide the optimal and most cost-effective Florida birth defect registry. For more information on studies, see Appendix 1: FBDR Studies and Evaluations.