

Tips for Using Florida Birth Defects Registry Data

- ❖ Defects with only a possible/probable diagnosis are in the registry
- ❖ Although the data include most birth defects, not all defects are collected. Some defects are related to gestational age, are normal variants, or result from other problems and will not be in the Florida data. Please review the defect coding instructions carefully for the defect of interest to be aware of any limitations or restrictions about the data. Examples: The heart defect, patent foramen ovale, is related to gestational age and not included unless certain conditions are met. When brain ventricles are enlarged as a result of bleeding in the brain (intraventricular hemorrhage), the enlarged ventricles are not included as a defect.
- ❖ A person can have more than one birth defect. In the Florida Birth Defects Registry, 50% of the cases have more than one birth defect. Each defect in a case is counted separately. Therefore, the data do not necessarily represent mutually exclusive cases. As a result, adding up the number of defects will not yield the number of infants with birth defects.
- ❖ Different birth defects can have different causes and affect different parts of the body. Studying or presenting all birth defects cases together rather than examining each specific defect is of limited value. Just as infectious disease data reports do not look at all infectious diseases combined but break the data out by the specific infectious disease (measles, shigella, AIDS, syphilis, SARs, toxoplasmosis, malaria, etc.), so should the birth defects data be examined.
- ❖ When examining data, a birth prevalence rate better reflects occurrences in a population than does the number of cases. This is because the number of cases is dependent on the size of the population being analyzed. The birth defect prevalence rate = $(\text{number of cases} / \text{total number of live births}) \times 10,000$, and is the customary method of reporting birth defects data. It is important to use the number of live births from the same population that produced the birth defects cases.
- ❖ Small numbers of cases can create analysis problems, such as unstable rate estimates. The small case numbers might result from the defect being rare or using a small population. The small numbers can show fluctuation in the data over time that may not be statistically significant.
- ❖ Some observed differences in frequencies and prevalence rates of specific birth defects is due to random variability. With relatively low birth prevalence, cases of particular conditions will be quite rare and the coincidence of two or more cases in space and/or time may be just that: a coincidence.