

# Birth Defects Tracking : Louisiana

## *Louisiana Birth Defects Monitoring Network*

The Louisiana Birth Defects Monitoring Network (LBDMN) is essential for understanding the impact of birth defects in the state. The program identifies babies with birth defects, collects information to learn about these conditions, and provides support to families of children with special healthcare needs in Louisiana.



### About the Program

LBDMN is a system that gathers basic information about the babies born in Louisiana with specific birth defects each year. One of 14 birth defects tracking programs that receive a grant funded by CDC's National Center on Birth Defects and Developmental Disabilities, the LBDMN monitors about 62,000 babies born in Louisiana each year.

LBDMN's goal is to develop an overall picture of birth defects in the state, promote resources for families of children with birth defects, and help prevent or reduce birth defects and other health problems in babies.



The LBDMN works to:

- Track over 70 birth defects, genetic conditions, and syndromes (including fetal alcohol syndrome) among babies and children younger than three years old in Louisiana.
- Help families of children with special healthcare needs by connecting families with local resources
- Identify populations at greater risk of having babies with birth defects or other health problems and provide health education to these populations

### Common. Costly. Critical.

- Of the 62,000 babies born each year in Louisiana, **at least 1,800 (1 out of 33) are born with a birth defect.**
- Birth defects are costly – **hospital costs for the treatment of birth defects are more than \$2.5 billion each year in the United States.**
- **Babies born with a birth defect are more likely to die before their first birthday,** compared to babies born without a birth defect.



**1 in 33**  
babies born in  
Louisiana has  
a major birth  
defect



## Making a Difference

The LBDMN developed the Family Resource Guide to benefit families with young children who visit the Children's Special Health Services Family Resource Center. The impact of this resource can be seen in this message from a mother of an infant with spina bifida and hydrocephalus:

“As a parent, receiving a diagnosis of serious birth defects, such as spina bifida and hydrocephalus is frightening. You get forced into this entirely new world full of medical terminology, insurance nightmares, and ‘systems’. Everyone you know has a small piece of information: ‘Sign up for this.’ ‘Get on the list for that.’ ‘You need to call this place.’ ‘I saw this place online.’ It is extremely overwhelming trying to gather, store, and research all of the information.

The Family Resource Guide takes all of the guesswork and confusion out of that. All of the information you need is in one place and easy to access. The information listed is all the most current available and no matter how much you click around, it is always easy to get right back to the beginning. It really is the light at the end of the tunnel.”

## Program in Action

- **Improves the tracking system:** The LBDMN has moved from a paper-based recording system to an electronic system. This transition will allow all information that has been collected about birth defects to be analyzed easily beginning in 2014. This web-based surveillance and referral system works with Louisiana Vital Statistics, Louisiana Newborn Genetic and Metabolic Screening, and Newborn Hearing and Screening programs.
- **Supports families:** The Family Resource Guide is an online service for families looking for information on state and local services that improve the lives of children with birth defects.



### For more information, please contact:

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