

Birth Defects Tracking : Kentucky

Kentucky Birth Surveillance Registry

The Kentucky Birth Surveillance Registry (KBSR) is essential for understanding the impact of birth defects in the state. The program promotes early and accurate identification of babies with birth defects and facilitates prevention, planning, and service delivery for families affected by birth defects in the state of Kentucky.



About the Program

For more than 10 years, the KBSR has served as the primary source of birth defects data in Kentucky. This birth defects tracking system partners with many state programs to refer babies and their families to appropriate health services in their communities. The registry also uses the birth defects data for prevention efforts. One of 14 birth defects tracking programs that receive a grant funded by CDC's National Center on Birth Defects and Developmental Disabilities, the KBSR monitors about 55,000 births per year.



The KBSR works to:

- Track birth defects in Kentucky and monitor trends over time
- Evaluate the timeliness and quality of the data on birth defects and referral to services
- Support education of the general public and health professionals about the causes, impact, and prevention of birth defects
- Facilitate research studies to help identify causes of birth defects
- Refer babies and their families to appropriate services in Kentucky

Common. Costly. Critical.

- In Kentucky, **nearly 3,000 babies** are born with one or more birth defects each year, and **about 350 pregnancies** a year end in a stillbirth.
- 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 18

babies born in
Kentucky has a
major birth
defect





Making a Difference

KBSR works with First Steps to connect children with a birth defect or disabling condition to local programs that provide early intervention services. This collaborative effort is helping to make sure that every baby in Kentucky receives the care he or she needs.

“Kentucky’s Early Intervention System (known as First Steps) has worked on increasing the number of children referred to early intervention before the age of 1 for several years. The trend indicates that the number of referrals of children ages birth to one year is increasing. Barriers that impeded referrals from the newborn surveillance program were diminished and an effective mechanism for referrals to the local First Steps offices implemented. Several local offices recorded referrals from the Kentucky Birth Surveillance Program for the first time. We have plans to expand the communication by developing electronic file exchanges in the future to continue this partnership.”

- Paula Goff, Part C Early Intervention Coordinator.

Counting Every Baby because Every Baby Counts



Program in Action

- **Prevent birth defects:** KBSR works to help prevent birth defects by:
 - Working with the Kentucky Folic Acid Partnership since 1997 to promote folic acid awareness. Folic acid is a B vitamin that can help prevent birth defects of the brain and spine, called neural tube defects. This collaboration led to the “Healthy Babies Are Worth the Wait” Community Toolkit and initiative. **KBSR has documented a 27% decrease in the number of babies born with neural tube defects in Kentucky between 2000 and 2007.**
 - Working with public schools to educate students about fetal alcohol syndrome. In September, Fetal Alcohol Syndrome Awareness Month, every public school principal in Kentucky receives an e-mail to share with all staff to spread the word that no alcohol is safe while pregnant.
 - Teaming up with the Kentucky Substance Exposed Infants Task Force to identify counties with the highest rates of substance exposure to target prevention and program planning.
- **Educate stakeholders about birth defects in Kentucky:** KBSR developed fact sheets about specific conditions to distribute to genetic clinics and the families they serve with information to help prevent birth defects in a subsequent pregnancy.
- **Track Birth Defects:** KBSR examines patterns in the occurrence of birth defects, and provides data to medical students, health professionals and researchers, and government officials.

For more information, please contact:

Kentucky Birth Surveillance Registry (KBSR)

(502) 564-4830 ext. 4394 * <http://chfs.ky.gov/dph/mch/ecd/kbsr.htm>