



Kentucky Birth Surveillance Registry (KBSR)

What is KBSR?

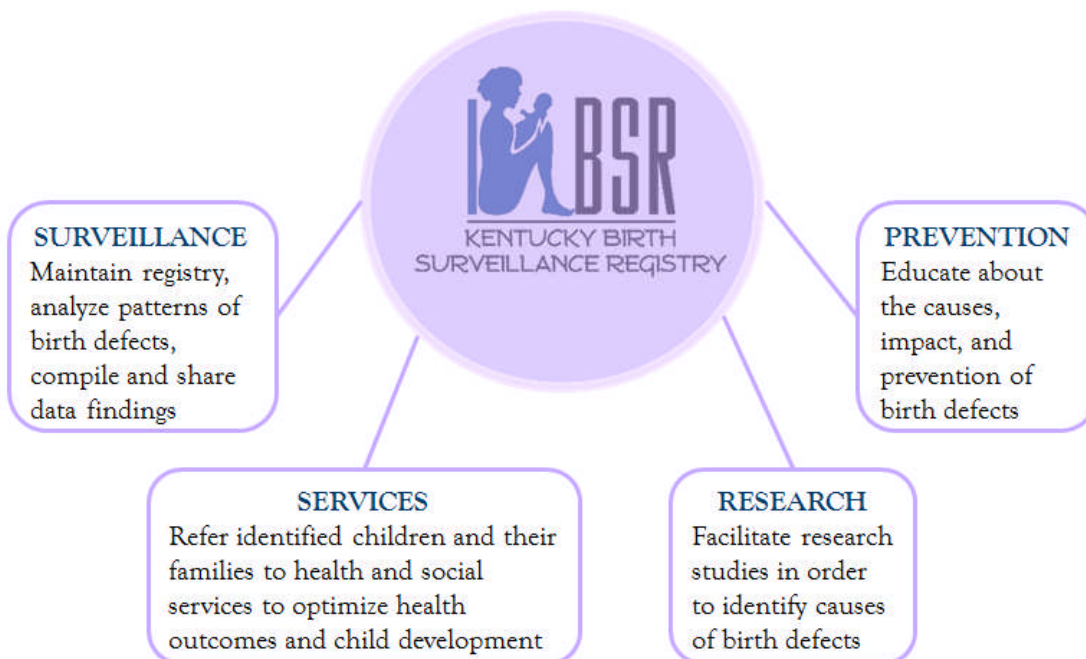
KBSR is a state-mandated surveillance system designed to provide information on the incidence, prevalence, trends, and possible causes of stillbirths, birth defects, and disabling conditions. In order to do so, KBSR collects information on children from birth to age five who are diagnosed with one or more of the conditions specified in Kentucky Administrative Regulations (902 KAR 19:010). Data comes from vital records, acute care and birthing hospitals, laboratories, other state agency surveillance systems, and genetics clinics. KBSR operates under the authority of Kentucky Revised Statute (KRS) 211.651-670.

Mission

The mission of KBSR is to promote early and accurate identification of children with birth anomalies and other disabling conditions in order to facilitate prevention, planning, and service delivery in the Commonwealth of Kentucky.

Since 1998, KBSR has been dedicated to:

- Preventing birth defects through ensuring timely, complete, and accurate birth defects **surveillance**;
- Referring children with birth defects to appropriate **services**;
- Providing data for **research** studies after appropriate review; and
- Implementing birth defects **prevention** programs in Kentucky.



What are Birth Defects?

Birth defects (or congenital anomalies) are health conditions that alter the structure of one or more body parts and occur during development in pregnancy.¹ Birth defects affect how the body looks, works, or both. Some problems are very minor and may require no interventions or can be corrected with surgery or therapy, while other birth defects can cause lifelong physical and/or mental disabilities. A birth defect may not affect the expected lifespan of the child; however, some birth defects can impact lifespan depending on the severity.

Birth Defects are Common

About 120,000 babies are born with a major birth defect in the U.S. every year, which is equivalent to 1 in every 33 births.¹



Every 4½ minutes, a baby is born with a birth defect in the United States.

In Kentucky, birth defects are even more common. Each year, about 4,900 babies (about 1 in every 12 births) have a birth defect, including major and minor birth defects, and those that are transient (naturally resolve on their own).

Birth Defects are Costly



Each year, total hospital costs for U.S. children and adults with birth defects exceed \$2.6 billion, not including outpatient care or many provider charges.

Birth defects cause pain and suffering for families, and the financial burden of caring for children with birth defects can be substantial. Often, babies born with birth defects need special treatments or services to thrive, adding to the costs of their care. The costs might be for a one-time surgery, or they might continue across a lifetime as ongoing treatment and intervention is needed. Families, communities, and the government share these costs.

Overall, from 2000 to 2010, the mean of total hospital charges was approximately six times greater for children with birth defects than for children without birth defects.² One component of the elevated costs is increased length of stay, as mean hospital stay for children with birth defects was more than twice that of those without.²

Birth Defects are Critical

Birth defects are a common cause of mortality among infants (babies under 1 year of age). In Kentucky and the U.S., about 20% of all infant deaths are caused by birth defects, which in Kentucky is the equivalent of about 81 cases per year.³ Birth defects are also implicated in about 45 stillbirths per year in Kentucky (about 13% of all reported stillbirths).

Birth defects cause

1 in every 5
deaths during the first year of life.



References

1. Centers for Disease Control and Prevention. Birth defects facts. National Center on Birth Defects and Developmental Disabilities. <http://www.cdc.gov/ncbddd/birthdefects/facts.html>. Last updated October 20, 2014. Accessed October 9, 2015.
2. Moffitt KB, Case AP, Farag NH, Canfield MA. Hospitalization charges for children with birth defects in Texas, 2001 to 2010. *Birth Defects Res A Clin Mol Teratol*. 2015 Dec 21. doi: 10.1002/bdra.23470.
3. Kentucky Department for Public Health. Public health child fatality review program 2016 annual report. <http://chfs.ky.gov/dph/mch/cfhi/childfatality.htm>. Accessed November 16, 2016.

Images made publicly available by the CDC. From "Birth Defects are Common, Costly, and Critical" infographic. <http://www.cdc.gov/ncbddd/birthdefects/infographic.html>