

What is the IBDPR?

The Indiana Birth Defects and Problems Registry (IBDPR) monitors birth defects and problems for babies born in Indiana. Hospitals, physicians and other healthcare providers are required by law to report birth defects to the IBDPR. Most birth defects are reported within the first year of life. However, birth defects can be reported up to age 3. Fetal alcohol syndrome (FAS) can be reported up to age 5. Autism spectrum disorders can be reported at any age.

What happens when a child's name is reported to the IBDPR?

A hospital or healthcare provider will inform the IBDPR that a child was diagnosed with a birth defect. The IBDPR does not share confidential information with anyone. The Indiana State Department of Health can plan services and provide resources based on the information received. All information about children and families reported to the IBDPR is confidential to respect the rights of families.

Where can parents go if they have questions?

Your child's doctor may have explained the details of your child's condition to you. Other services and support may be available to you and your family. Please visit our website for a list of resources. Please contact your doctor if you have any questions or concerns about your child's condition.



www.birthdefects.in.gov

Information from the IBDPR is important to:

- Link parents of infants with birth defects to necessary services
- Find ways to reduce the impact of birth defects
- Identify factors associated with birth defects
- Prevent birth defects through education and awareness programs
- Reduce infant deaths due to birth defects

Birth Defects and Infant Deaths

An infant death is defined as the death of a baby before his/her first birthday. Birth defects are a leading cause of infant deaths. About 1 in 5 infant deaths are due to birth defects. Birth defect monitoring programs provide information and ensure programs are in place to give babies with birth defects the services they need.



For more information, please visit the IBDPR website www.birthdefects.in.gov or email IBDPR@isdh.in.gov



Indiana State
Department of Health

Genomics & Newborn
Screening Program



Information Parents Need to Know about Birth Defects

Indiana Birth Defects
and Problems Registry



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What is a birth defect?

A birth defect is a change in the body that is present at birth. Birth defects are also called congenital anomalies. Birth defects can change how the body looks, works or grows. Birth defects that effect how the body looks are called structural birth defects. Birth defects that effect how the body works or grows are called functional birth defects.

Common birth defects include:

- Atrial septal defect
- Ventricular septal defect
- Hypospadias
- Down syndrome
- Cleft palate/cleft lip

What causes birth defects?

More research is needed to better understand additional causes of birth defects, but most birth defects occur in the first three months of pregnancy. The first trimester is when the baby's tissues are developing. Some birth defects are hereditary, but there is something you can do. Unhealthy behaviors may also cause birth defects, so it is important to practice healthy behaviors, like exercising, healthy eating and hand washing to prevent infections.

Factors that increase the chance of having a baby with a birth defect:

- Smoking, drinking alcohol, taking drugs
- Obesity
- Uncontrolled diabetes
- Some medications
- Family history
- Having twins or multiples
- High risk pregnancies



Can birth defects be prevented?

Some, but not all birth defects can be prevented. There are steps you can take before and during pregnancy to reduce the risk of having a baby with a birth defect.

Make a PACT to reduce the chance of having a baby with a birth defect:

- Plan ahead
 - See your doctor regularly
 - Take folic acid
- Avoid Harmful Substances
 - Don't drink alcohol, smoke or take drugs
 - Protect yourself from infections by avoiding animal droppings, sick people, unpasteurized milk products, and insects that carry viruses, such as Zika
- Choose a healthy lifestyle
 - Maintain a healthy weight
 - Keep diabetes or other chronic conditions under control
- Talk to your healthcare provider
 - Start prenatal care as soon as you think you are pregnant
 - Tell your doctor about any medications you may be taking
 - Talk about any vaccinations (shots) you may need

When will I know if my baby has a birth defect?

Some birth defects can be found during pregnancy by special screening tests. Some birth defects will not be found until birth or later. Birth defects, like cleft lip, are seen right after birth, but others, such as chromosomal anomalies, are found using special tests. Your child's doctor should talk to you about any concerns they have during pregnancy or after birth.

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Will my child with a birth defect need special care?

Your child may need special care and interventions to help your child live and grow to the best of his/her ability. The type of care needed will be based on the birth defect. Some birth defects require lifelong care. Medications, surgeries and regular doctor visits may be needed. The earlier care is received the better the outcomes will be for your child.

How many babies are born with birth defects?

- About 1 in every 33 babies each year are born with a birth defect
- That's about 120,000 babies a year or one baby every 4-1/2 minutes

