

Does New Jersey offer services if my baby has a birth defect?

Yes. When a child is registered, a copy of the registration is sent to the SCHS County Case Management Unit where you live.

A case manager is assigned to your child's case and will be in contact with you.

The case manager can help you locate services that you or your child may need, such as:

- Early Intervention Services, if eligible
- Financial aid for a catastrophic illness
- Special summer camps
- Help with durable medical equipment
- Other services and resources in your county

Contacts:

New Jersey Department of Health
State Birth Defects Registry
PO Box 364
Trenton, NJ 08625
Phone: 609-292-5676

For Early Intervention Services for infants and toddlers under 3 years old with developmental delays and disabilities, call the Early Intervention System Telephone Referral Line:
Phone: 1-888-653-4463

For children birth through 21 years old with special health care needs and chronic medical conditions, call the Special Child Health Services Case Management Unit for the listing of a case management unit in your county of residence:
Phone: 609-777-7778

A Brochure for Parents and Families with Children with Birth Defects



For Parents and Families with Children with Birth Defects

For more information, go to:

www.cdc.gov/ncbddd/birthdefects/facts.html
<http://nj.gov/health/fhs/sch/schr.shtml>



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Governor
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Lt. Governor



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Commissioner



Helping children reach endless potentials



New Jersey Birth Defects Registry (BDR)

Facts:

- Every 4 ½ minutes a baby is born with a birth defect in the United States, according to the Centers for Disease Control and Prevention (CDC).
- In New Jersey, about 20 babies are born each day with a birth defect.
- With over 100,000 births each year, the New Jersey Birth Defects Registry (BDR) tracks more than 8,000 babies with birth defects and connects them to needed services.

What is a birth defect?

A birth defect is any physical, mental or chemical abnormality present at birth (like Down Syndrome, PKU, or cleft palate).

What causes birth defects?

For some birth defects, like fetal alcohol syndrome, we know the cause. However, for most birth defects, the cause is not known. If you have any questions about a birth defect, talk to your primary healthcare provider or doctor.

What are the most common birth defects?

In New Jersey, the most common birth defects are congenital heart defects. Other common defects are Down syndrome, club feet, and cleft lip and palate.

How can the Birth Defects Registry (BDR) help you?

The BDR connects children to the Special Child Health Services (SCHS) Case Management Unit of the New Jersey Department of Health. Case managers are assigned to each registered child to help families find the services they need to help care for their child.



History

The history of the Registry dates back to 1926 when the Crippled Children's Program was created to help children with orthopedic conditions, such as club feet and polio, receive State aid. In 1983, the name changed to the Birth Defects Registry, and more conditions were added.

Who must be registered?

Children are registered if they:

- ❖ Have a birth defect
- ❖ Are younger than 6 years of age, and
- ❖ Live in New Jersey or become a resident of New Jersey



Who registers my child?

The following are required to register:

- The hospital where your child was born
- The hospital where your child received care
- The doctor or medical office where your child was diagnosed with a birth defect

What information does the Registry contain?

- Child's name, date of birth and other birth information
- Parent(s) name and date of birth (if no biological parent is mentioned, the name of the guardian)
- Child's Address
- Reporting facility
- Information about the birth defect(s)

Can I refuse to have my child registered?

State law requires that the hospital or health care professional who makes a birth defects diagnosis must register the information with the BDR. Your consent is not required to have your child registered. However, the hospital or the person reporting your child should inform you of the registration process.

Is the information in the Registry confidential?

Yes. This is a confidential Registry. Information submitted to the BDR by a reporting facility, such as a hospital or a doctor's office, is not shared with anyone or with any agency without your consent. Information is kept in a secure computer system.

How is the collected information used?

The information collected by the BDR is used to refer children to case management services. It is also used to collect information on the numbers and types of defects reported in New Jersey.