Birth Defects Resources

Learning about your child's special health care needs can help you be sure they are getting the right care and interventions.

Visit these websites for comprehensive information on different types of birth defects, healthy outcomes for mothers and babies, and support programs in your area.

The Centers for Disease Control and Prevention

cdc.gov/ncbddd/birthdefects

The March of Dimes

marchofdimes.org

The Partnership for Maternal & Child Health of Northern New Jersey

partnershipmch.org

Central Jersey Family Health Consortium

cjfhc.org

Southern New Jersey Perinatal Cooperative

snjpc.org

For More Information

New Jersey Department of Health Birth Defects Registry

Contact us with questions about your child's registration. 609-292-5676 nj.gov/health/fhs/bdr

Early Intervention Services

Available for infants and toddlers under 3 years old with developmental delays and disabilities. Contact the New Jersey Early Intervention System. 888-653-4463 nj.gov/health/fhs/eis

Case Management Services

Available for children birth up to 22 years old with special health care needs and chronic medical conditions. Contact the Special Child Health Services Case Management Unit for the case management unit in your county of residence. 609-777-7778 nj.gov/health/fhs/specialneeds/ case-management

Children with Special Health Care Needs

Information for Parents and Families about the New Jersey Birth Defects Registry





Introduction

Learning that your child has been diagnosed with a birth defect is an emotional time for families. While you are celebrating your new baby, it is normal to feel various emotions and uncertainty about what to do next. Depending on the type of birth defect, your baby may need specialized care and services as they grow and develop.

The New Jersey Birth Defects Registry, also called the New Jersey Special Child Health Services Registry, is one way to ensure your child is referred to services as soon as possible.

What are birth defects?

The term birth defect refers to a variety of conditions which are present at birth. They affect different parts of the body, such as the limbs, heart or spine. Chromosomal disorders and hearing loss at birth are also considered birth defects. Signs and symptoms can range from mild to severe.

Birth defects are common. According to the Centers for Disease Control and Prevention (CDC), every year, one in 33 babies is born with a birth defect in the United States.

Why have a Birth Defects Registry?

In addition to linking families to services, the Registry also helps us understand how common different types of birth defects are in New Jersey.

New Jersey state law requires birth facilities and other health care professionals to register any New Jersey child up to age 6 who is diagnosed with a birth defect.

What causes birth defects?

Some birth defects have known causes, such as drinking alcohol or taking certain medications during pregnancy, but for most the cause is unknown.

Not all birth defects can be prevented, but there are things you can do to decrease the chances of your baby having a birth defect.

Scan the QR code below to download tips on having a healthy pregnancy.



What happens after my child is registered?

You will receive a letter informing you that your child has been registered with the Special Child Health Services Registry, and that someone in your county's Case Management Unit will contact you to offer information and support. The Registry and Case Management are confidential. To ensure your family's privacy is protected, no specific information about your child's diagnosis is included in the letter.

What services are available for my child?

We refer registered children to New Jersey Department of Health's Special Child Health Services (SCHS) Case Management Unit. A case manager from your home county can assist you with finding resources and services specific to your child's needs. Scan the QR code below to view a brochure about Case Management services. Participation is voluntary and available until age 22.

