

# Birth Defects Tracking : Rhode Island

## Rhode Island Birth Defects Program

The Rhode Island Birth Defects Program (RIBDP) is essential for understanding the impact of birth defects in the state. The program identifies babies and children with birth defects and assures that these children receive the health services they need in a timely manner.



### About the Program

The RIBDP is a system that tracks the number of babies born with birth defects each year and tries to understand what causes birth defects. One of 14 birth defects tracking programs that receive a grant funded by CDC's National Center on Birth Defects and Developmental Disabilities, the RIBDP monitors about 10,500 babies born in Rhode Island each year. The program works closely with healthcare providers, community partners, and families to improve services available to children with birth defects and their families, as well as develop strategies to help mothers reduce their chance of having a baby with a birth defect.



The RIBDP works to:

- Identify children in Rhode Island up to age five who have a birth defect
- Understand who is at risk in order to develop strategies to help reduce birth defects and address issues of burden and disparity
- Connect families of babies with a birth defect with local resources and services on a timely basis
- Develop preventive and educational strategies that target women who are at increased risk for having a baby with a birth defect

### Common. Costly. Critical.

- Of the 10,500 babies born in Rhode Island each year, **about 500 babies (1 in 21) are born with a birth defect.**
- Birth defects are costly – **hospital costs for the treatment of birth defects are more than \$2.5 billion each year in the United States.** Between 2008 and 2010, total hospital costs for newborns with a birth defect in Rhode Island were about \$102 million, **which translates to \$64,000 per newborn with a birth defect.**
- **Babies born with a birth defect are more likely to die before their first birthday, compared to babies born without a birth defect. Among the 79 Rhode Island infants who died in 2010, 15 (19%) of those deaths were due to a birth defect.**

**1 in 21**  
babies born in  
Rhode Island  
has a major  
birth defect





## Program in Action

- **Promotes folic Acid:** Through a collaboration with the Rhode Island Family Planning Program, multivitamins containing folic acid have been distributed to over 1,000 women. These multivitamins can help prevent some serious birth defects of the brain and spine.
- **Improves birth defects tracking:** In Rhode Island, birth defects are a reportable condition. The RIBDP has developed an online reporting system for physicians, pediatric practices, and laboratories to report birth defects to the RIBDP. This allows the RIBDP to track birth defects across the state.
- **Disseminates data:** The RIBDP shares information with healthcare providers, policy makers, community organizations, and families to increase awareness about birth defects.



“The Rhode Island Department of Health Birth Defects Program has been instrumental in helping us track the care of our patients in the craniofacial program. Their commitment to careful data collection allows us to monitor referrals and improve comprehensive care for these children.”

*- Helena Taylor, MD, PhD, Chief of Craniofacial Surgery, Rhode Island Hospital and Assistant Professor of Plastic Surgery, Brown University Warren Alpert Medical School*

- **Educates healthcare professionals:** January is National Birth Defects Prevention Month. During this month, RIBDP coordinates with the March of Dimes and Children's Hospital to schedule presentations for pediatric healthcare providers that bring attention to birth defects. Community partners and families are also invited to participate in these presentations.
- **Refers to services:** The RIBDP wants to make sure that families of children with birth defects are able to receive the referrals and services they need. Families of children with birth defects can fill out forms, which are condition-specific, to tell RIBDP about the medical, developmental, educational and support services they received. RIBDP continually works to fill gaps in family support referrals and services that are identified through this process.

### For more information, please contact:

Rhode Island Birth Defects Program

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