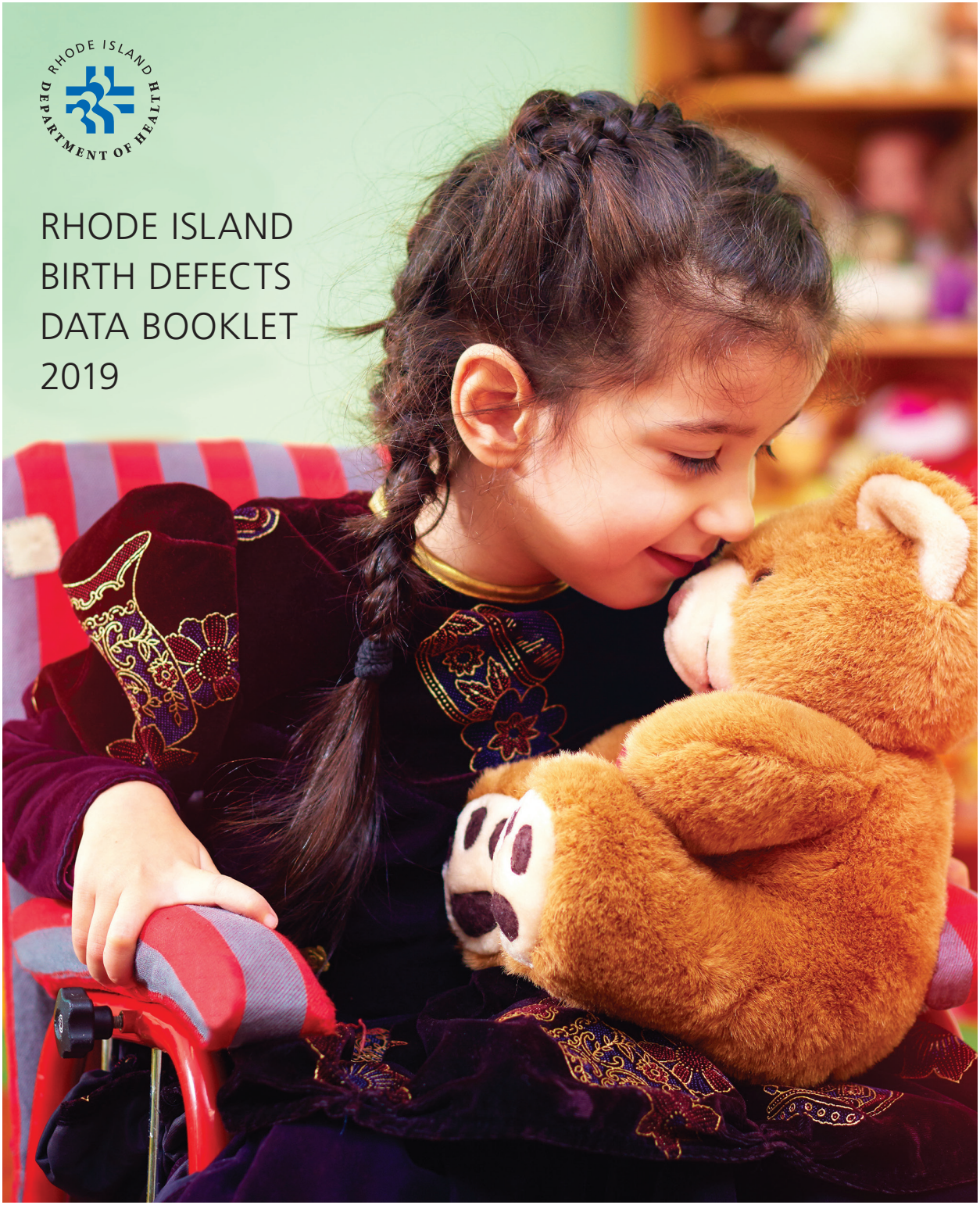
RHODE ISLAND BIRTH DEFECTS DATA BOOKLET 2019



BIRTH DEFECTS SURVEILLANCE IN RHODE ISLAND

Birth defects are structural abnormalities that affect the development of organs and tissues of an infant or child. These abnormalities may be identified during pregnancy, at birth, or following birth. Possible causes or contributing factors of birth defects include genetics, environmental pollutants, occupational hazards, diet, medications, and personal behaviors.

Early recognition of, and response to, birth defects often prevents more serious effects. A birth defects surveillance and information system is essential for the development of programs and policies that can reduce birth defects and infant mortality. At the Rhode Island Department of Health (RIDOH), the Rhode Island Birth Defects Program (RIBDP) maintains this surveillance system. The RIBDP identifies newborns with birth defects; assures that these children receive appropriate preventive, specialty, and other healthcare services; and monitors trends over time. All information collected by the RIBDP is confidential and is protected under state and federal privacy laws.

All healthcare providers are mandated by regulation to report cases of birth defects identified among children, up to age 5, to the RIBDP. The reporting of birth defects cases helps the RIBDP assure that these children receive appropriate services and referrals on a timely basis and helps identify children who were not diagnosed with a birth defect at the time of birth. The RIBDP also works with all five birthing hospitals to capture birth defects diagnosed at birth using hospital discharge data.

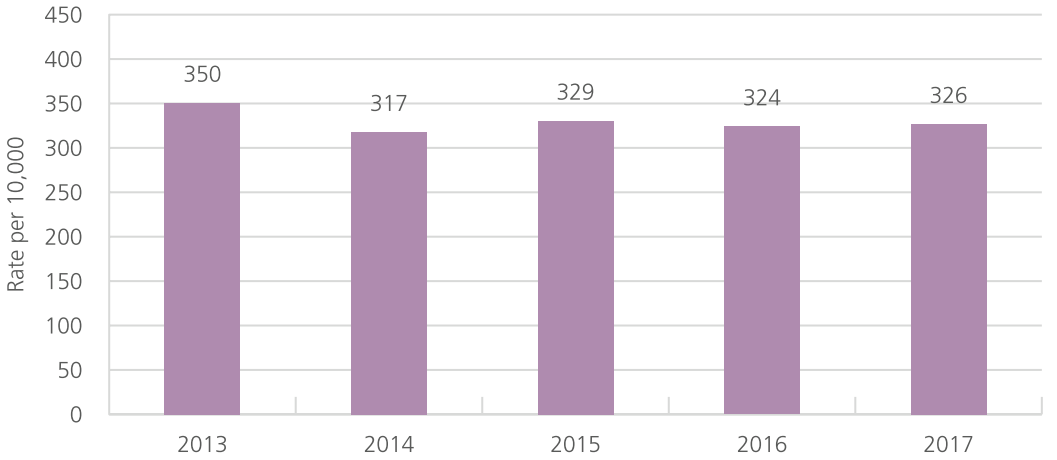
Birth defects cases include children born to Rhode Islanders, from birth up to age five, and are identified using the 10th clinical modification of the International Classification of Diseases (ICD 10-CM) codes for diagnoses. The RIBDP confirms the accuracy of reported birth defects diagnoses through chart review and follows birth defects surveillance guidelines developed by the National Birth Defects Prevention Network (NBPDN).

In the United States, a baby is born with a birth defect every 4.5 minutes.

Identification of Cases During the Newborn Period

From 2013 to 2017, the birth defects rate decreased by 7% from 350 per 10,000 live births in 2013 to 326 per 10,000 live births in 2017, after adjusting for the updated birth defects case definition (Figure 1).

FIGURE 1: *Prevalence of Birth Defects Cases, Rhode Island, 2013-2017*



Source: *Rhode Island Birth Defects Program, RIDOH*

There is no known safe amount, no safe time, and no safe type of alcohol to drink during pregnancy.

The overall prevalence rate of birth defects from 2013 to 2017 was 329 cases per 10,000 live births (Table 1). Cardiovascular defects were the most common type of defect (131 per 10,000). Other common birth defects in Rhode Island include those related to musculoskeletal (119 per 10,000) and genitourinary (85 per 10,000) systems.

TABLE 1: *Cases and Prevalence of Birth Defects by Body System, Rhode Island, 2013-2017*

BIRTH DEFECT	NUMBER OF CASES	RATE (PER 10,000 LIVE BIRTHS)
Cardiovascular	708	131
Central Nervous System	106	20
Chromosomal	92	17
Eye Ear Face Neck	60	11
Gastrointestinal	116	22
Genitourinary	457	85
Musculoskeletal	639	119
Orofacial	77	14
Respiratory	48	9
All birth defects	**2,353**	**437**
All birth defects cases	**1,774**	**329**

Source: *Rhode Island Birth Defects Program, RIDOH*

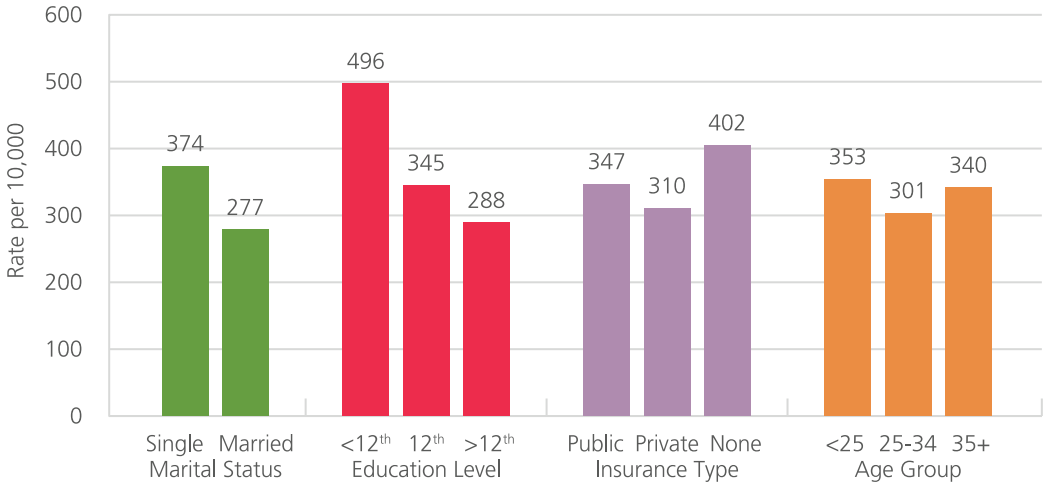
Note: The All birth defects row represents all birth defects diagnosed in Rhode Island from 2013-2017. The All birth defects cases row represents the total number of Rhode Island babies born from 2013-2017 with at least one diagnosed birth defect.

The use of marijuana and other drugs during pregnancy can lead to preterm birth and birth defects.

Maternal Risk Factors

Babies born to women with certain maternal characteristics were at a higher risk of having a birth defect (Figure 2). From 2013 to 2017, women who were unmarried, had less than a high school education, were insured through public programs (such as RIte Care and Medicaid) or had no insurance, and were younger than 25 were more likely to have a baby born with a birth defect.

FIGURE 2: *Prevalence of Birth Defects by Selected Maternal Characteristics, Rhode Island, 2013-2017*



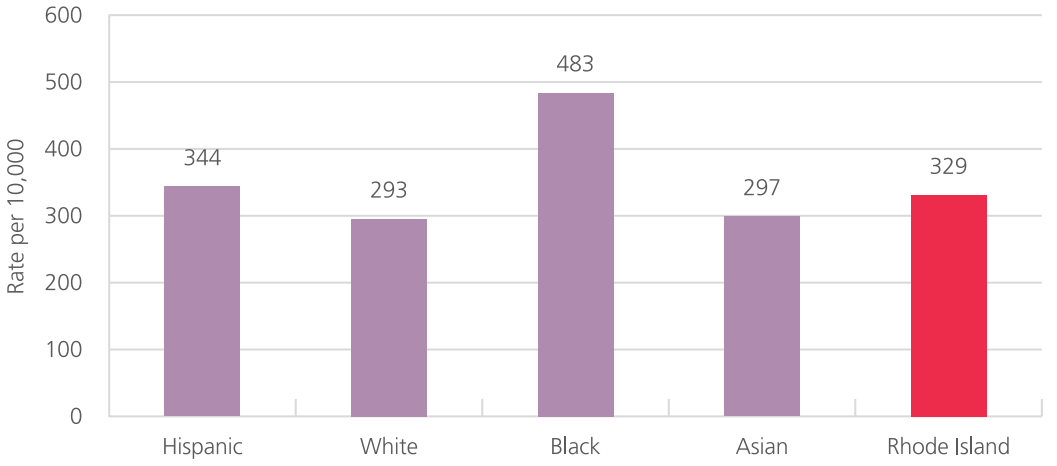
Source: *Rhode Island Birth Defects Program, RIDOH*

Proper management of chronic conditions, such as diabetes, can help prevent birth defects and other poor outcomes.

Racial/Ethnic and Geographic Disparities

Birth defects prevalence also varies by race/ethnicity (Figure 3) and by geography (Figure 4). During 2013-2017, non-Hispanic Blacks/African Americans and Hispanics had higher birth defects rates than non-Hispanic Whites and non-Hispanic Asians. The birth defects prevalence rate for non-Hispanic Asians and non-Hispanic Whites was lower than the Rhode Island prevalence rate for this timeframe.

FIGURE 3: *Prevalence of Birth Defects by Race/Ethnicity, Rhode Island, 2013-2017*



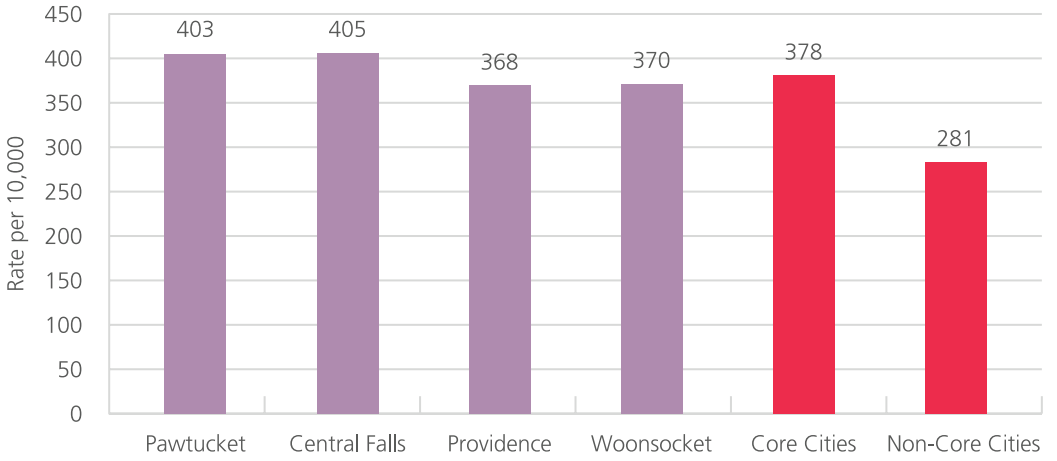
Source: *Rhode Island Birth Defects Program, RIDOH*

Smoking during pregnancy increases the chances of premature birth, certain birth defects, and infant death.

Babies born to residents of core cities where the poverty level is higher than 25% (Central Falls, Pawtucket, Providence, and Woonsocket) were about 1.3 times more likely to have a birth defect than babies born to residents living in the rest of the state (Figure 4).

Central Falls and Pawtucket, which had two of the highest birth defects rates in the state, have higher rates of teen pregnancy, low birth weight, late prenatal care (prenatal care started in the third trimester or no prenatal care), and poverty compared to the rest of the state.

FIGURE 4: *Prevalence of Birth Defects by Selected Geographic Areas, Rhode Island, 2013-2017*



Source: *Rhode Island Birth Defects Program, RIDOH*

Obesity before and during pregnancy increases the risk of several serious birth defects.

Service Assessments

A priority of the RIBDP is to assure that children with birth defects receive appropriate and timely preventive, specialty, and other healthcare services. The RIBDP, in collaboration with the Rhode Island Parent Information Network (RIPIN), employs a Parent Consultant who conducts service assessments with families who have children up to the age of five with specific birth defects to determine whether these children have received appropriate referrals and services on a timely basis. The Parent Consultant meets with families at pediatric and specialty care practices that service children with birth defects or mails forms to those families who cannot be interviewed in a practice.

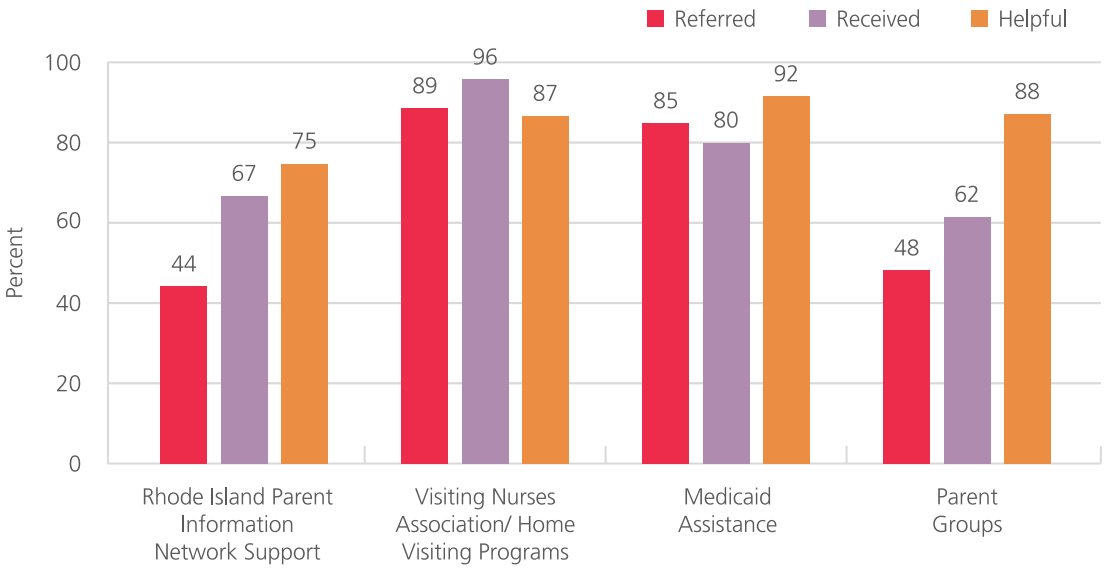
Service assessments help the RIBDP determine what services and referrals were provided to children based on the national guidelines for specific conditions. The RIBDP has conducted more than 800 service assessments from 2011 - 2018.

Service assessments are currently conducted with families of children who have Down Syndrome, spina bifida, craniofacial defects, critical congenital heart defects, abdominal wall defects, hearing loss, and microcephaly or other central nervous system conditions.

During 2011 to 2018, 54 families completed service assessments for children with spina bifida, and 40 (74%) completed more than one assessment. The majority (91%) of the initial assessments were conducted at specialty clinics.

For family support services (Figure 5), the highest referral rates were for the Visiting Nurses Association (VNA)/Home Visiting (89%) and Medicaid assistance (85%). There were fewer referrals to RIPIN (44%) and parent support groups (48%), and families were not likely to receive these services once referred. Of all families who received support services, the majority said they found them to be helpful.

FIGURE 5: *Family Support Service Referral and Receipt by Families of Children with Spina Bifida, Rhode Island, 2011-2018*

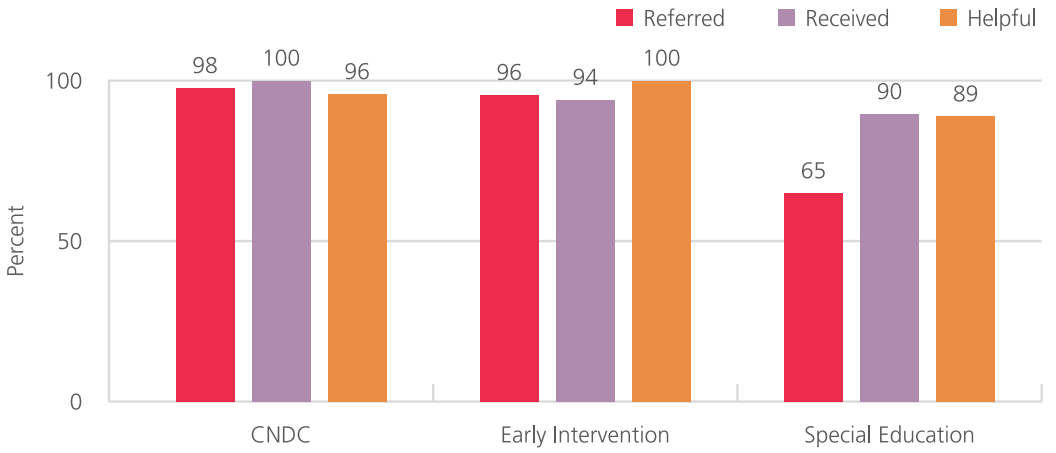


Source: *Rhode Island Birth Defects Program, RIDOH*

Some infections a mother gets before or during pregnancy can hurt her and her baby.

Families eligible for developmental and educational services were more likely to be referred to the Children's Neurodevelopmental Center (CNDC) at Hasbro Children's Hospital (98%) and Early Intervention (96%) than special education (65% of children age three or older) (Figure 6). Families were likely to receive services and were highly satisfied with these services once referred.

FIGURE 6: *Educational and Developmental Support Service Referral and Receipt by Families of Children with Spina Bifida, Rhode Island, 2011-2018*



Source: *Rhode Island Birth Defects Program, RIDOH*

It is recommended that women take 400-800 micrograms (mcg) of folic acid every day, starting at least one month before getting pregnant.

Prevention Activities

Although not all causes of birth defects are known, there are many things a woman can do before and during pregnancy to reduce the risk of having a baby with a birth defect. These include getting routine prenatal check-ups; taking folic acid supplements before and during pregnancy; avoiding tobacco, alcohol, and other substances; eating a healthy diet; getting appropriate levels of exercise; preventing exposure to chemicals; and managing existing medical conditions (diabetes, epilepsy, and high blood pressure).

The RIBDP works with RIDOH's Family Planning Program to purchase and distribute multivitamins with folic acid to uninsured women who receive a negative pregnancy test at family planning clinics. Additionally, the program also collaborates with the Women's Facility at the Rhode Island Department of Corrections to distribute multivitamins with folic acid to women who are incarcerated.

Data Dissemination and Partnerships

Sharing data and information on birth defects with healthcare providers, policy makers, community organizations, families, and other stakeholders can increase awareness of birth defects and lead to program enhancements and policy development. The RIBDP uses a multi-pronged approach to data dissemination, which includes maintaining an up-to-date website; publishing studies in peer-reviewed journals; presenting information at state, local, and national meetings; and sponsoring grand rounds at local hospitals.

The RIBDP participates in collaborative studies with the NBDPN to gain a better understanding of specific birth defects and their causes. The RIBDP also works in partnership with its Advisory Council, which includes representatives from Women & Infants Hospital, Hasbro Children's Hospital, the March of Dimes Rhode Island/Southeastern Massachusetts market, and RIPIN. The Advisory Council provides guidance to the RIBDP in the development and implementation of its surveillance, prevention, service assurance, and information dissemination strategies.

For more information on birth defects and links to resources, please visit our website.
www.health.ri.gov/birthdefects

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Funding for this publication is from a cooperative agreement with the Centers for Disease Control and Prevention
(Grant Number: NU50DD004943-01)

October 2019