VERMONT
DEPARTMENT OF HEALTH

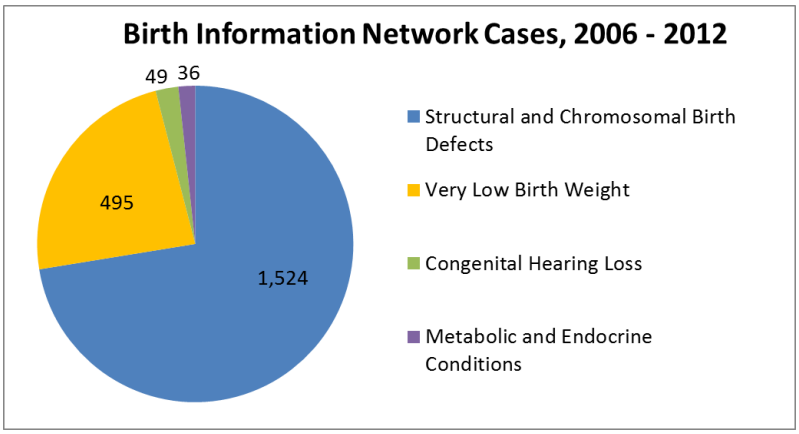
Birth Information Network: 2006 – 2012

Introduction:

Birth defects are common, costly, and critical conditions that affect 1 in every 33 babies born in the United States each year. This report presents an overview of the Birth Information Network (BIN) at the Vermont Department of Health. The program monitors trends, promotes prevention, and links families to resources. Statewide data from the BIN are included for the birth cohort years of 2006 to 2012, along with analyses of several related topics.

Background:

The Birth Information Network (BIN) was established by Vermont legislation in 2003 (18 V.S.A. § 5087) to conduct statewide, population-level surveillance of selected structural birth defects and other congenital conditions in order to improve outreach and referral services for families with children with special health needs, ensure adequate services are available for children and their families, evaluate efforts to prevent health problems and document possible links between environmental and chemical exposure with the special health conditions of Vermont's infants and children.



In 2006, the Vermont Birth Information Network began collecting information about Vermont-resident children diagnosed in the first year of life with one or more of 33 structural and chromosomal birth defects, seven metabolic and endocrine conditions, congenital hearing loss, and very low birth weight (infant born with a birth weight less than 1500 grams). In 2011, additional legislation was passed authorizing the BIN to collect information on two additional conditions, upper and lower limb reduction, starting with 2010 births.

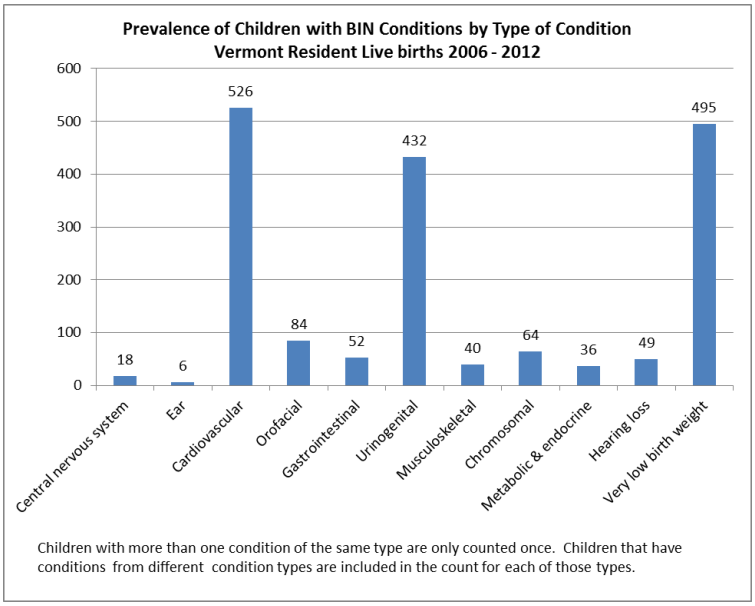
The BIN uses multiple data sources to identify potential cases and then conducts follow up to confirm or rule out those cases. At the time of the program's start, it relied on predominantly on four data sources: Medicaid claims, reports from Vermont hospitals and physicians, vital records, and records maintained by the Vermont Department of Health's Children with Special Health Needs program (CSHN). The 2011 legislation also specifically authorized the BIN to collect information from the Vermont Healthcare Claims Uniform Reporting and Evaluation System (VHCURES), a recently developed All Payers claims dataset. Since then the VHCURES dataset has been used for case ascertainment and case follow up purposes.

Prevalence:

From 2006 through 2012, of the 43,786 infants born to Vermont residents, 1,624 (3.7%) were known to have one or more of the conditions monitored by the BIN. As a group, structural and chromosomal birth defects were the most common type of condition in the BIN, with 1,119 (2.6%) of infants having at least one of these conditions. Very low birthweight, was the next most predominant with 495 infants (1.1%), followed by 49 congenital hearing loss (0.11%), and 36 infants (0.08%) with metabolic or endocrine conditions.

An infant may have more than one birth defect. Of the 1,119 infants born from 2006 to 2012 with at least one significant structural or chromosomal birth defect, 263 (24%) had more than one birth defect.

Cardiovascular conditions affected the most children with 526 children having at least one cardiovascular condition. This was followed by 495 children with very low birth weight and 432 children with at least one urogenital condition.



Mortality:

The infant death rate (i.e., infant died before one year of age) for infants born from 2006 to 2012 that have any of the conditions monitored by the BIN was 88.7 deaths per 1,000. This compares to an infant death rate of 4.9 deaths per 1,000 live births for all resident infants. When mortality is broken down by condition type, very low birth weight had the highest death rate of 232 per 1,000 children born with very low birth weight. Structural and chromosomal birth defects have a death rate of 38.4 per 1,000 children born with at least one of those conditions. No Vermont resident children born from 2006 to 2012 with hearing or metabolic or endocrine conditions died within the first year of life.

The data highlight and reinforce the need to address birth defects as part of public health efforts aimed at reducing infant mortality. The BIN is preparing to start collecting data on a revised standard set of birth defects conditions starting with the 2016 birth cohort.

Frequency and Prevalence of Conditions in the Vermont Birth Information Network
Vermont Resident Live Births 2006 – 2012

Group	Condition	Cases per Births	Number of Cases
Central nervous system		1 in 2433	18
	Anencephalus	1 in 10947	4
	Encephalocele	1 in 21893	2
	Spina bifida without anencephalus	1 in 3649	12
Ear		1 in 7298	6
	Anotia / microtia	1 in 7298	6
Cardiovascular		1 in 83	526
	Aortic valve stenosis	1 in 1990	22
	Atrial septal defect	1 in 170	258
	Coarctation of aorta	1 in 1368	32
	Common truncus	1 in 10947	4
	Ebstein's anomaly	1 in 43786	1
	Endocardial cushion defect	1 in 1990	22
	Hypoplastic left heart syndrome	1 in 3368	13
	Patent ductus arteriosus	1 in 584	75
	Pulmonary valve atresia and stenosis	1 in 674	65
	Tetralogy of Fallot	1 in 1990	22
	Transposition of great arteries	1 in 2576	17
	Tricuspid valve atresia and stenosis	1 in 10947	4
	Ventricular septal defect	1 in 160	274
Orofacial		1 in 521	84
	Cleft lip with and without cleft palate	1 in 932	47
	Cleft palate without cleft lip	1 in 1183	37
Gastrointestinal		1 in 842	52
	Esophageal atresia / tracheoesophageal fistula	1 in 3128	14
	Rectal and large intestinal atresia / stenosis	1 in 1990	22
	Small intestinal atresia	1 in 2305	19
Urinogenital		1 in 101	432
	Bladder extrophy	1 in 14595	3
	Epispadias	-	0
	Hypospadias	1 in 128**	176
	Obstructive genitourinary defect	1 in 178	246
	Renal agenesis / hypoplasia	1 in 1990	22
Musculoskeletal		1 in 1095	40
	Diaphragmatic hernia	1 in 2576	17
	Gastroschisis	1 in 3368	13
	Omphalocele	1 in 14595	3
	Reduction deformity, upper limbs	1 in 3052	6***
	Reduction deformity, lower limbs	1 in 9155	2***
Chromosomal		1 in 684	64
	Down syndrome	1 in 768	57
	Trisomy 13 (Patau's syndrome)	1 in 43786	1
	Trisomy 18 (Edwards' syndrome)	1 in 7298	6
Metabolic & endocrine		1 in 1216	36
	Biotinidase deficiency	*	*
	Congenital hypothyroidism	1 in 1412	31
	Galactosemia	-	0
	Homocystinuria	*	*
	Maple syrup urine disease	-	0
	Phenylketonuria	*	*
	Sickle cell disease and other hemoglobinopathies	*	*
Hearing loss		1 in 894	49
Very low birth weight (<1500 g)		1 in 88	495

Vermont has about 6,250 live births each year, thus the number of cases are very small for the rarer conditions, making it difficult to distinguish random changes from true changes in the data. The Vermont Newborn Screening Program, the source of much of the information on the metabolic and endocrine cases, has requested that for such conditions where the total number is less than six cases that the number of cases and rate be suppressed and displayed as "*". As the other conditions in this report have already been published elsewhere, they are not suppressed here.

** Since hypospadias is a condition of the male genitalia, it is presented in terms of male live births.

*** Reduction deformity, lower limbs and Reduction deformity, upper limbs were added by legislation passed in 2011, starting with 2010 births.