

# NEURAL TUBE DEFECTS IN UTAH

1995-2015

*UTAH BIRTH DEFECT NETWORK*

*BUREAU OF CHILDREN WITH  
SPECIAL HEALTH CARE NEEDS*

*UTAH DEPARTMENT OF HEALTH*



UTAH DEPARTMENT OF  
**HEALTH**  
Utah Birth Defect Network

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## List of Figures and Tables

Figures	Page
Figure 1: Functions of the Utah Birth Defect Network	4
Figure 2: Distribution by Pregnancy Outcome, Utah Birth Defect Network, 1995-2015	12
Figure 3: Distribution by Etiology, Utah Birth Defect Network, 1995-2015	13
Figure 4: Prevalence Rates of Neural Tube Defects in Utah, Utah Birth Defect Network, 1995-2015	13
Figure 5: Prevalence Rates of Neural Tube Defects by 3-Year Groups, Utah Birth Defect Network, 1995-2015	14
Figure 6: Prevalence Rates of Neural Tube Defects by Age, Utah Birth Defect Network, 1995-2015	14
Figure 7: Prevalence Rates of Neural Tube Defects by Race/Ethnicity, Utah Birth Defect Network, 1995-2015	14
Figure 8: Prevalence Rates of Neural Tube Defects by Pre-Pregnancy Body Mass Index (BMI), Utah Birth Defect Network, 1995-2015	15
Figure 9: Prevalence Rates of Neural Tube Defects by Number of Previous Pregnancies, Utah Birth Defect Network, 2009-2015	15
Figure 10: Prevalence Rates of Neural Tube Defects by Diabetes Status, Utah Birth Defect Network, 2009-2015	16
Figure 11: Prevalence Rates of Neural Tube Defects by Trimester of First Prenatal Care Visit, Utah Birth Defect Network, 2009-2015	16
Figure 12: Distribution of Folic Acid Awareness among Utah Women Aged 18-44, Utah Behavioral Risk Factor Surveillance System, 2012-2016	17
Figure 13: Distribution of Folic Acid Knowledge among Utah Women Aged 18-44, Utah Behavioral Risk Factor Surveillance System, 2012-2016	17
Figure 14: Distribution of Folic Acid Consumption among Utah Women Ages 18-44, Utah Behavioral Risk Factor Surveillance System, 2012-2016	18
Tables	Page
Table 1: Disease Classification Codes of Neural Tube Defects	7
Table 2: Characteristics of Women with High Prevalence by Neural Tube Defect, Utah Birth Defect Network, 1995-2015	11
Table 3: Distribution by Pregnancy Outcome, Utah Birth Defect Network, 1995-2015	19
Table 4: Distribution by Etiology, Utah Birth Defect Network, 1995-2015	19
Table 5: Prevalence Rates of Neural Tube Defects in Utah, Utah Birth Defect Network, 1995-2015	19
Table 6: Prevalence Rates of Anencephaly by Characteristics, Utah Birth Defect Network, 1995-2015	19 – 20
Table 7: Prevalence Rates of Spina Bifida by Characteristics, Utah Birth Defect Network, 1995-2015	20 – 21
Table 8: Prevalence Rates of Encephalocele by Characteristics, Utah Birth Defect Network, 1995-2015	22 – 23
Table 9: Folic Acid Awareness among Utah Women Aged 18-44, Utah Behavioral Risk Factor Surveillance System, 2012-2016	23
Table 10: Folic Acid Knowledge among Utah Women Aged 18-44, Utah Behavioral Risk Factor Surveillance System, 2012-2016	23
Table 11: Folic Acid Consumption among Utah Women Aged 18-44, Utah Behavioral Risk Factor Surveillance System, 2012-2016	23

## Executive Summary

The Utah Birth Defect Network (UBDN) is a statewide population-based surveillance system that monitors major structural birth defects of all pregnancy outcomes (live births, stillbirths, and terminations) among Utah resident women. The mission of the UBDN is to prevent birth defects and secondary disabilities by monitoring occurrence, referring to services, facilitating research, and providing education and outreach to children and families in Utah. The UBDN is a program under the Utah Department of Health Bureau of Children with Special Healthcare Needs. The aims of this report are to (1) highlight the trend of neural tube defects in the Utah and (2) to describe the characteristics of women who have experienced a pregnancy affected by a neural tube defect.

Neural tube defects are birth defects impacting the brain, spine, and spinal cord during early fetal development. The three neural tube defects reported in this report are anencephaly, spina bifida, and encephalocele. In Utah, the prevalence of neural tube defects has remained stable between 1995 and 2015. The overall prevalence of anencephaly, spina bifida, and encephalocele in Utah from 1995-2015 were 2.3 per 10,000 live births, 4.0 per 10,000 live births, and 1.0 per 10,000 live births respectively.

High rates for specific neural tube defects were seen among populations with specific characteristics. For anencephaly, high rates were seen among women who were 19 years of age and younger, identified as Hispanic or Latina, were obese (pre-pregnancy BMI  $\geq 30$ ), had six or more previous pregnancies, had pre-existing diabetes, or did not have prenatal care. For spina bifida, high rates were seen among those who were 40 years of age or older, identified Hispanic or Latina, were obese (pre-pregnancy BMI  $\geq 30$ ), had six or more previous pregnancies, or had no prenatal care. For encephalocele, high rates were seen among those who were 19 years of age and younger, identified as Hispanic or Latina, were obese (pre-pregnancy BMI  $\geq 30$ ), or had 1-5 previous pregnancies.

There is high awareness and knowledge about folic acid and its benefits for preventing birth defects; however, utilization of folic acid remains low among Utah women aged 18-44. Consuming 400 micrograms (mcg) of folic acid once a day can help reduce the risk of having a pregnancy with a neural tube defect. The UBDN health education and outreach team promote birth defect prevention by providing education and distributing bottles of multivitamins with folic acid to community members. Women can do their part to reduce their risk of having an infant with a birth defect by engaging in healthy lifestyles before, during, and after pregnancy. The UBDN recommends Utah women do what is “**Best for You. Best for Baby**” with these five tips.

- **Tip 1:** Be sure to take 400 micrograms (mcg) of folic acid every day.
- **Tip 2:** Book a visit with your healthcare provider before stopping or starting any medication.
- **Tip 3:** Become up-to-date with all vaccines, including the flu shot.
- **Tip 4:** Before you get pregnant, try to reach a healthy weight.
- **Tip 5:** Boost your health by avoiding harmful substances during pregnancy, such as alcohol, tobacco, and other drugs.

For more information on how to prevent birth defects, visit: <https://www.nbdpn.org/bdpm.php>.

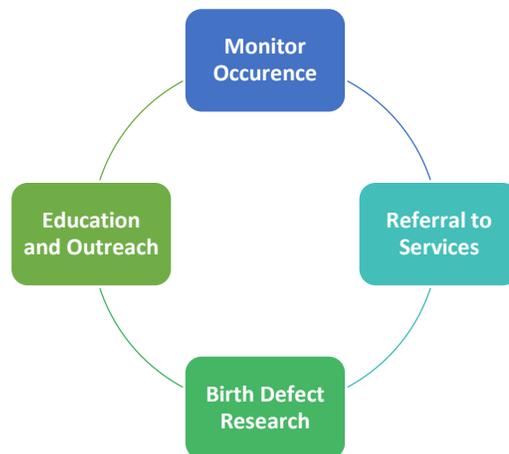
For questions about this report, visit the UBDN website: <https://health.utah.gov/cshcn/programs/ubdn.html>.

## Introduction

### Utah Birth Defect Network

The Utah Birth Defect Network (UBDN) is a statewide population-based surveillance system that monitors major structural birth defects of all pregnancy outcomes (live births, stillbirths, and terminations) among Utah resident women. The mission of the UBDN is to prevent birth defects and secondary disabilities by monitoring occurrence, referring to services, facilitating research, and providing education and outreach to children and families in Utah as shown in Figure 1. The UBDN is a program under the Bureau of Children with Special Healthcare Needs, Division of Family Health and Preparedness within the Utah Department of Health. The aims of this report are to (1) highlight the trend of neural tube defects in the Utah and (2) to describe the characteristics of women who have experienced a pregnancy affected by a neural tube defect.

Figure 1: Functions of the Utah Birth Defect Network



### Neural Tube Defects

Neural tube defects are birth defects impacting the brain, spine, and spinal cord during fetal development [10]. During the first weeks of pregnancy, the fetus develops a neural tube which later becomes the spinal cord [10, 11]. With a neural tube defect; the neural tube does not completely close and leaves an opening along the spine [10]. This exposes critical structures and impacts essential motor and cognitive functions [10, 11]. Infants who are born with neural tube defects face serious health outcomes that can lead to lifelong disability and even death [10]. The presence of neural tube defects can have financial and emotional impact on children and families [10]. Three major neural tube defects are anencephaly, spina bifida, and encephalocele [10, 11].

Anencephaly is a birth defect in which a part of the brain and skull does not develop [2]. This is due to upper parts of the neural tube incorrectly closing and results in a fetus without the front part of the brain [2]. Those born with anencephaly usually die prior to or soon after delivery [2]. Infants born with this condition are usually deaf, blind, and unable to feel pain [11]. Anencephaly is a lethal neural tube defect [2].

Spina bifida is a birth defect in which the spine does not fully close during development and leaves the spinal cord exposed [6]. This leads to damage of the spinal cord and related nerves [6]. Those born with spina bifida have physical disabilities ranging in severity depending on size and location of the defect or lesion [6]. An infant born with spina bifida usually has paralysis below the lesion which leads to difficulties walking, and bowel or urinary problems [11]. Spina bifida is the most common neural tube defect in the United States [6].

Encephalocele is a birth defect in which the brain and its membranes protrude out of an opening in the skull in a sac-like structure [4]. This is due to incomplete closing of the neural tube near the brain [4]. This sac-like structure can occur anywhere along the center of the skull but is usually found at the back of the head [4]. Encephalocele is usually identified right after birth and those with encephalocele can show signs of loss of strength in the arms and legs, smaller heads, and physical and intellectual disabilities [4, 11].

### Risks and Causes

Neural tube defects are the result of a combination of environmental and genetic factors [7]. The exact cause of neural tube defects can be difficult to identify because each affected pregnancy may have had different causes [7]. Causes of neural tube defects are organized into four categories [8]:

1. Genetic disorders
2. Exposure to an environmental hazard
3. Maternal illness during pregnancy
4. Lack of necessary nutrients

Certain populations have a higher risk for neural tube defects. This includes women who have had a previous pregnancy with a neural tube defect, women who are obese, women who identify as Hispanic or Latina, and women who did not have enough B-vitamin folate or folic acid during the first weeks of pregnancy [5, 8].

### Folic Acid

Folic acid, also known as folate, is a B vitamin that helps the body develop [9]. Folate is naturally found in foods such as leafy greens, beans, and citrus fruits [12]. Folic acid is man-made and found in multivitamins and prenatal vitamins [12]. Although folate is naturally found in foods, past studies showed women were still not receiving enough daily amounts of folate to effectively reduce their risk for neural tube defects [13]. In 1998, through the efforts of the birth defects community, folic acid became readily available through vitamins and fortification of foods such as bread, cereal, and pasta [12, 13]. Since then, rates of neural tube defects have decreased across the United States [1]. The UBDN supports the national recommendation by the Centers for Disease Control and Prevention (CDC) and the United States Preventive Service Task Force to encourage women to take 400 micrograms (mcg) of folic acid once a day before, during, and after pregnancy to reduce their risk of having a pregnancy affected by a neural tube defect. Since neural tube defects can occur before most women realize they are pregnant, it is important to incorporate folic acid use into everyday diet [9, 12, 13].

## Methodology

This report describes characteristics among Utah women who have had a pregnancy affected by a neural tube defect but does not make conclusions about any associations or correlations between these characteristics and the risk of having a pregnancy affected by an neural tube defect.

### Data Sources

The main data sources used for this report were the UBDN, Utah Vital Records, and the Behavioral Risk Factor Surveillance System (BRFSS). In order to be registered as a birth defect case by the UBDN, the child or fetus must have a major structural or functional birth defect, the mother must be a Utah resident, and the child or fetus must be reported to the UBDN by two years of age. All pregnancy outcomes (i.e. live births, stillbirths, and terminations) were included in this analysis.

Data on pregnancies affected by neural tube defects were derived from the UBDN. Denominator data, or number of live births, were derived from the Utah Birth Certificate data from the Utah Department of Health Office of Vital Records and Statistics.

Data from the BRFSS were used to assess knowledge and behaviors surrounding folic acid use among Utah residents. The BRFSS is an annual telephone survey conducted by the Utah Department of Health Office of Public Health Assessment. Seven folic acid questions were included in the annual BRFSS survey for all years 2000-2004 and during even years starting in 2006-present. Women ages 18-44 were asked questions regarding folic acid awareness, knowledge, and use. This report includes BRFSS data from 2012, 2014, and 2016. For information on the methodology of the BRFSS, visit:

[http://health.utah.gov/oph/OPHA\\_BRFSS.htm](http://health.utah.gov/oph/OPHA_BRFSS.htm).

### Calculations

Prevalence rates, the total number of individuals in a population who have the health outcome at a specific period of time divided by the size of the population at the specific time period, was used in the report. Prevalence rates are calculated as:

$$\frac{\text{Number of cases of selected birth defect}}{\text{Number of live births}} \times 10,000$$

The 95% confidence intervals were calculated for each rate. If the lower limit and upper limit of the confidence interval contains 0.0 then the rate is considered not statistically significant at a value greater than 5% level ( $p > 0.05$ ).

### Case Definition

Neural tube defects were categorized using the CDC and British Pediatric Association Classification of Diseases (BPA) codes, also known as CDC/BPA. Anencephaly codes were 740.00 to 740.10. Spina bifida (without anencephaly) codes were 741.00 to 741.99 (without 740.00 – 740.10). Encephalocele codes were 742.00 to 742.09. Please see table below for associated ICD9-CM and ICD10-CM codes.

Table 1: Disease Classification Codes of Neural Tube Defects

	CDC/BPA	ICD9-CM	ICD10-CM
Anencephaly	741.00 – 741.10	740.0 – 740.1	Q00.0 – Q00.1
Spina bifida (without Anencephaly)	741.00 – 741.10 (without 741.00 – 741.10)	741.0 or 741.9 (without 740.0 – 740.1)	Q05.0 – Q05.9 or Q07.03 (without Q00.0 – Q00.1)
Encephalocele	742.00 – 742.09	742.0	Q01.0 – Q01.9

**Characteristics**

For this report, age, race/ethnicity, pre-pregnancy Body Mass Index (BMI), number of previous pregnancies, diabetes status, and trimester of first prenatal care visit of women who had a pregnancy with a neural tube defect were analyzed. Age was categorized as ≤19, 20-24, 25-29, 30-34, 35-39, and ≥40. Race/ethnicity was categorized as non-Hispanic White, non-Hispanic Black or African American, Hispanic or Latina, non-Hispanic Asian or Pacific Islander, and non-Hispanic American Indian or Alaskan Native. BMI was categorized as underweight (<18.5), normal weight (18.5 to <25), overweight (25 to <30), and obese (≥30). Number of previous pregnancies was categorized as zero, one to five, and six or more. Diabetes status was categorized as none, gestational, and pre-existing. Trimester of first prenatal care visit was categorized as none, first trimester (≤12 weeks), second trimester (13-26 weeks), and third trimester (≥27 weeks).

**Strengths and Limitations**

The strength to this report is quality data on neural tube defects. An additional strength is the time span of the report which extends into years prior to folic acid fortification (1998). A limitation to this report is a limited number of characteristics were included. Understanding potential characteristics with higher rates allows for better understanding of high risk populations and health disparities. Another limitation is the data for number of previous pregnancies, diabetes status, and trimester of prenatal care was restricted to 2009-2015 due to incomplete data and changes in data collection.

**Suggested Reference**

Huynh M., Johnson J., Robinson S., Smith P., Lechminant K., Rawson T., Frank A., Southwick J., Despain S., Dugan S., Carey J., Nance A.. (2019). *Prevalence of Neural Tube Defects in Utah, 1995 – 2015*. Utah Birth Defect Network Website: Research & Data.

## Results

### Overall

- There were a total of 750 pregnancies affected by a neural tube defect between 1995 and 2015 in Utah.
- 62.5% of pregnancies affected by neural tube defects resulted in a live birth. The distribution by pregnancy outcomes are shown in Figure 2 and Table 3.
- Of the 750 pregnancies, 70.9% were isolated; meaning the case only had one birth defect present. The distribution by isolated defects vs. multiple is shown in Figure 3 and Table 4.
- The overall rate of anencephaly, spina bifida, and encephalocele in Utah were 2.3 per 10,000 live births, 4.0 per 10,000 live births, and 1.0 per 10,000 live births respectively. The results are shown in Figure 4 and Table 5.

### Anencephaly

- The highest rate of anencephaly was from 1995-1997 and 2007-2009 at 2.7 per 10,000 live births compared to other 3-year groups (Figure 5).
- Women with the highest rate of anencephaly were  $\leq 19$  years old at 2.9 per 10,000 live births compared to women of other age groups (Figure 6).
- Women who identified as Hispanic or Latina had the highest rate of anencephaly compared to women of other races/ethnicities at 3.4 per 10,000 live births (Figure 7).
- Women who were considered obese or had a pre-pregnancy BMI  $\geq 30$  had the highest rate of anencephaly compared to women of other pre-pregnancy BMI groups at 2.9 per 10,000 live births (Figure 8).
- Women who had  $\geq 6$  previous pregnancies had the highest rate of anencephaly compared to women who had  $< 6$  previous pregnancies at 4.5 per 10,000 live births (Figure 9).
- Women with pre-existing diabetes had the highest rate of anencephaly at 14.8 per 10,000 live births compared to women of other diabetes status (Figure 10).
- Women who received no prenatal care had the highest rate of anencephaly at 25.3 per 10,000 live births compared to women who did receive prenatal care (Figure 11).

### Spina Bifida

- The highest rate of spina bifida was from 2004-2006 at 4.7 per 10,000 live births compared to other 3-year groups (Figure 5).
- Women with the highest rate of spina bifida were  $\geq 40$  years old at 5.3 per 10,000 live births compared to women of other age groups (Figure 6).
- Women who identified as Hispanic or Latina had the highest rate of spina bifida compared to women of other races/ethnicities at 4.2 per 10,000 live births (Figure 7).
- Women who were considered obese or had a pre-pregnancy BMI  $\geq 30$  had the highest rate of spina bifida compared to women of other pre-pregnancy BMI groups at 4.6 per 10,000 live births (Figure 8).
- Women who had  $\geq 6$  previous pregnancies had the highest rate of spina bifida compared to women who had  $< 6$  previous pregnancies at 5.8 per 10,000 live births (Figure 9).

- Women who received no prenatal care had the highest rate of spina bifida at 31.6 per 10,000 live births compared to women who did receive prenatal care (Figure 11).

### Encephalocele

- The highest rate of encephalocele was from 2013-2015 at 1.6 per 10,000 live births compared to other 3-year groups (Figure 5).
- Women with the highest rate of encephalocele were  $\leq 19$  years old at 1.4 per 10,000 live births compared to women of other age groups (Figure 6).
- Women who identified as Hispanic or Latina Hispanic or Latina had the highest rate of encephalocele compared to women of other races/ethnicities at 1.3 per 10,000 live births (Figure 7).
- Women who were considered obese or had a pre-pregnancy BMI  $\geq 30$  had the highest rate of encephalocele compared to women of other pre-pregnancy BMI groups at 1.2 per 10,000 live births (Figure 8).
- Women who had 1-5 previous pregnancies had the highest rate of encephalocele at 1.2 per 10,000 live births compared to women who had no previous pregnancies or  $\geq 6$  previous pregnancies (Figure 9).

### Folic Acid

- Among women aged 18-44 in Utah, between 80.4% and 82.1% had heard of or were aware of folic acid as shown in Figure 12 and Table 9.
- Between 48.4% and 52.5% of Utah women aged 18-44 knew healthcare professionals recommended folic acid to prevent birth defects as shown in Figure 13 and Table 10.
- Consumption of folic acid is low among women 18-44 in Utah with between 37.6% and 38.3% currently taking a multivitamin or vitamin pill/supplement containing folic acid as shown in Figure 14 and Table 11.
- Data from the BRFSS showed although awareness and knowledge about folic acid are high; the consumption of folic acid remains low among women ages 18-44 in Utah. This supports community efforts to educate women on folic acid as well as distribute bottles of multivitamins containing folic acid.

## Community Efforts

Health education and outreach is one of the main functions of the UBDN. Our health education and outreach team is composed of two health educators who educate women about folic acid and distribute bottles of multivitamins with folic acid at community events. Since folic acid consumption is a known protective factor for neural tube defects, the UBDN team focuses efforts on folic acid awareness and utilization among women of reproductive age (18-44).

Since 2016, the UBDN team has attended 147 community events. Twenty-five events took place in 2016, 49 in 2017, and 73 in 2018. The UBDN team distributed 21,831 bottles of multivitamins containing folic acid; 12,886 educational materials on birth defects; 8,035 power your life bags containing information on preconception health; and 13,792 UBDN promotional items (pens, manicure sets, nail files, Frisbees, sunglasses, and lip balm). Successful events include Birth Defect Prevention Month, Folic Acid Awareness Week, World Birth Defect Day, World Down Syndrome Day, and Men's Health Week.

The UBDN folic acid campaign occurs the 2<sup>nd</sup> week of January for National Folic Acid Awareness Week. During this week, the UBDN health education and outreach team conduct an educational campaign to spread awareness about the importance of folic acid. Using Facebook, the UBDN team publishes a sponsored post where women can take a survey to receive a free 3-month supply of multivitamins containing 400 mcg of folic acid. This campaign has been successful in increasing the distribution of folic acid in Utah and in reaching women in communities where staff are not able to participate in events.

If you are interested in reaching out to the UBDN health education and outreach team visit: <https://health.utah.gov/cshcn/programs/ubdn.html>.



## Recommendations

Certain characteristics have been highlighted as having higher rates of neural tube defects compared to other characteristics. The table below highlights the characteristics with high rates of neural tube defect. Identifying certain characteristics with high rates helps the UBDN team identify and develop specific and targeted campaigns for at-risk populations.

Table 2: Characteristics of Women with High Prevalence by Neural Tube Defect, Utah Birth Defect Network, 1995-2015

Anencephaly	Spina Bifida	Encephalocele
≤19 years old	≥40 years old*	≤19 years old*
Hispanic or Latina	Hispanic or Latina	Hispanic or Latina
Obese (Pre-pregnancy BMI ≥30)	Obese (Pre-pregnancy BMI ≥30)	Obese (Pre-pregnancy BMI ≥30)
≥6 previous pregnancies*	≥6 previous pregnancies*	1-5 previous pregnancies
Pre-existing Diabetes*		
No Prenatal Care*	No Prenatal Care*	

\*Use caution in interpreting, the estimate has a relative standard error greater than 30% and does not meet UDOH standards for reliability. Rates for number of previous pregnancies, diabetes status, and trimester of first prenatal care visit were restricted to data from 2009-2015.

The majority of birth defects have unknown causes [5]. Previous birth defect research shows birth defects are influenced by a combination of environmental, behavioral, and genetic factors [5]. Birth defect research is ongoing in order to understand how to reduce the risk of birth defects among women of childbearing age and better serve children and families. The UBDN serves families of Utah by monitoring the occurrence of birth defects, referring families to appropriate services, facilitating birth defect research, and providing education and outreach. In order to reduce the risk of birth defects, the UBDN recommends women aged 18-44 engage in healthy lifestyles before, during, and after pregnancy. The UBDN recommends Utah women do what is **“Best for You. Best for Baby”** with these five tips.

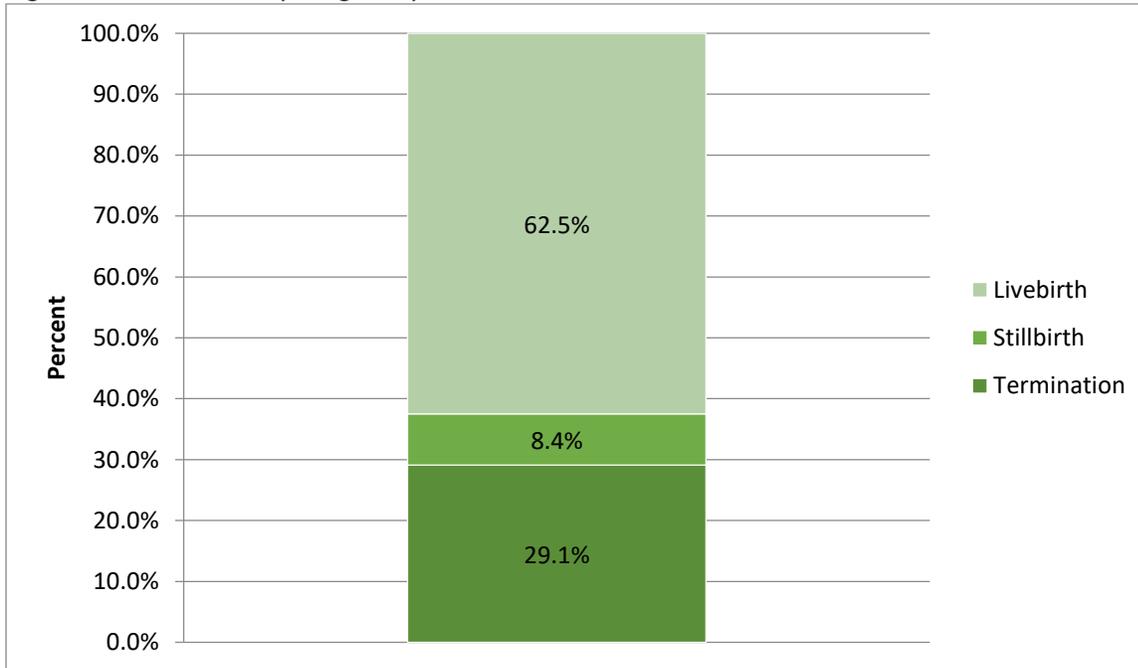
- **Tip 1:** Be sure to take 400 micrograms (mcg) of folic acid every day
- **Tip 2:** Book a visit with your healthcare provider before stopping or starting any medication
- **Tip 3:** Become up-to-date with all vaccines, including the flu shot
- **Tip 4:** Before you get pregnant, try to reach a healthy weight
- **Tip 5:** Boost your health by avoiding harmful substances during pregnancy, such as alcohol, tobacco, and other drugs

For more information on how to prevent birth defects, visit: <https://www.nbdpn.org/bdpm.php>.

For questions about this report, visit the UBDN website at: <https://health.utah.gov/cshcn/programs/ubdn.html>.

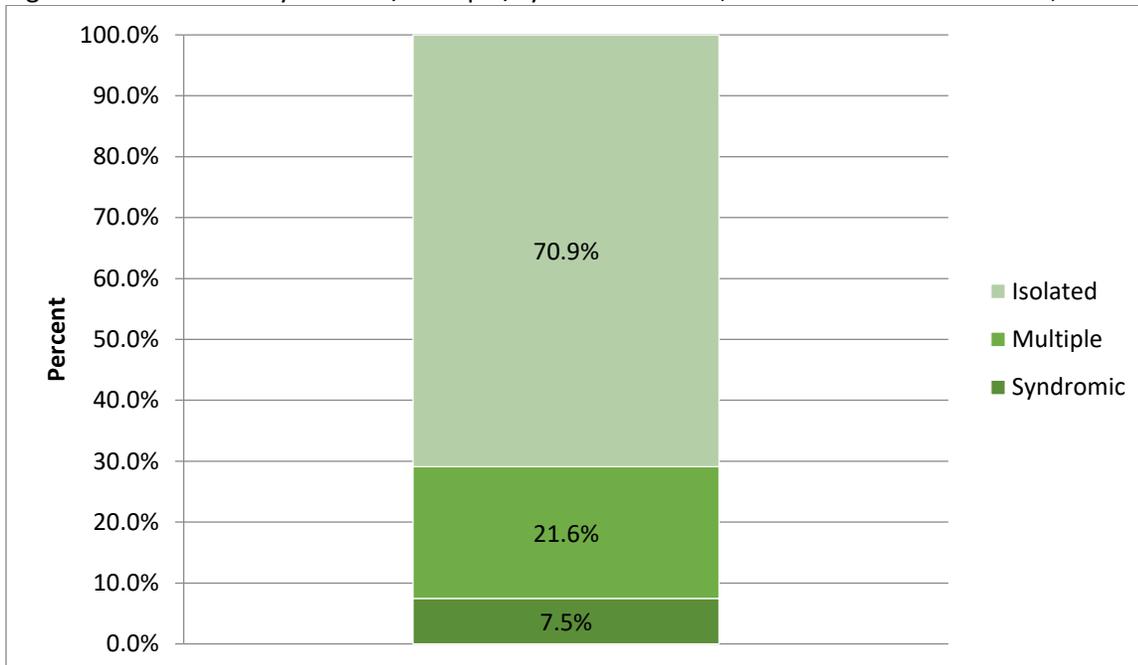
## Figures

Figure 2: Distribution by Pregnancy Outcome, Utah Birth Defect Network, 1995-2015



Note: Live birth = birth where child is born alive; Stillbirth = birth where child has died in the womb after 20 weeks of pregnancy; Termination = elective ending of a pregnancy.

Figure 3: Distribution by Isolated/Multiple/Syndromic Status, Utah Birth Defect Network, 1995-2015



Note: Isolated = has one birth defect; Multiple = has multiple birth defects; Syndromic = has a set of symptoms or signs that make up a recognizable condition of known cause.

Figure 4: Prevalence Rates of Neural Tube Defects in Utah, Utah Birth Defect Network, 1995-2015

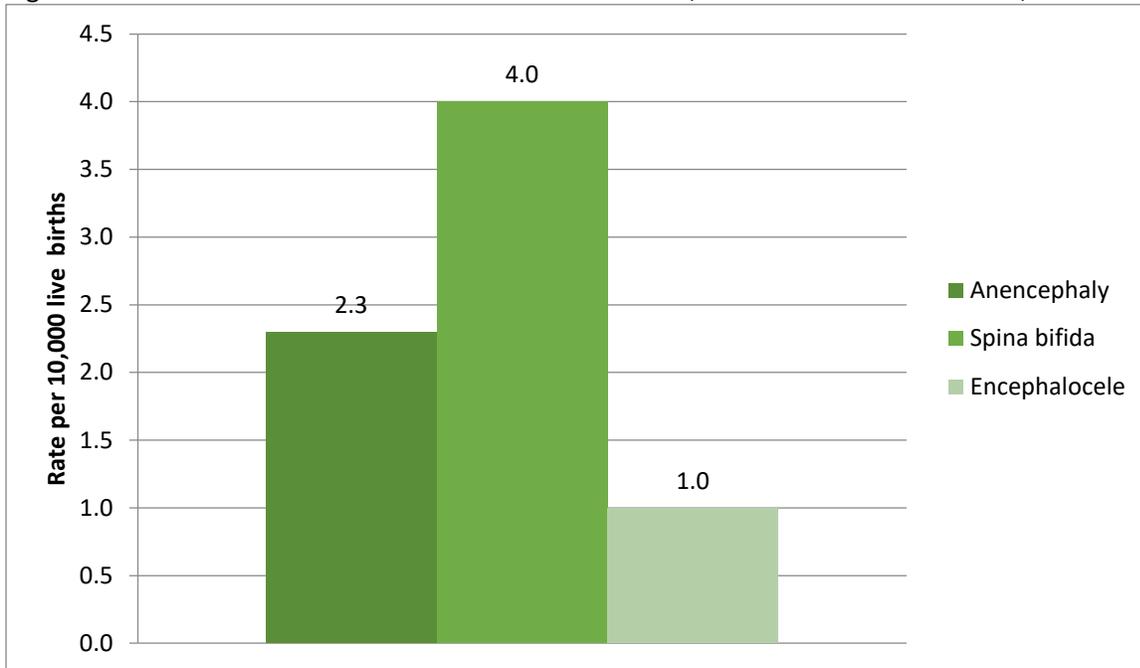


Figure 5: Prevalence Rates of Neural Tube Defects by 3-Year Groups, Utah Birth Defect Network, 1995-2015

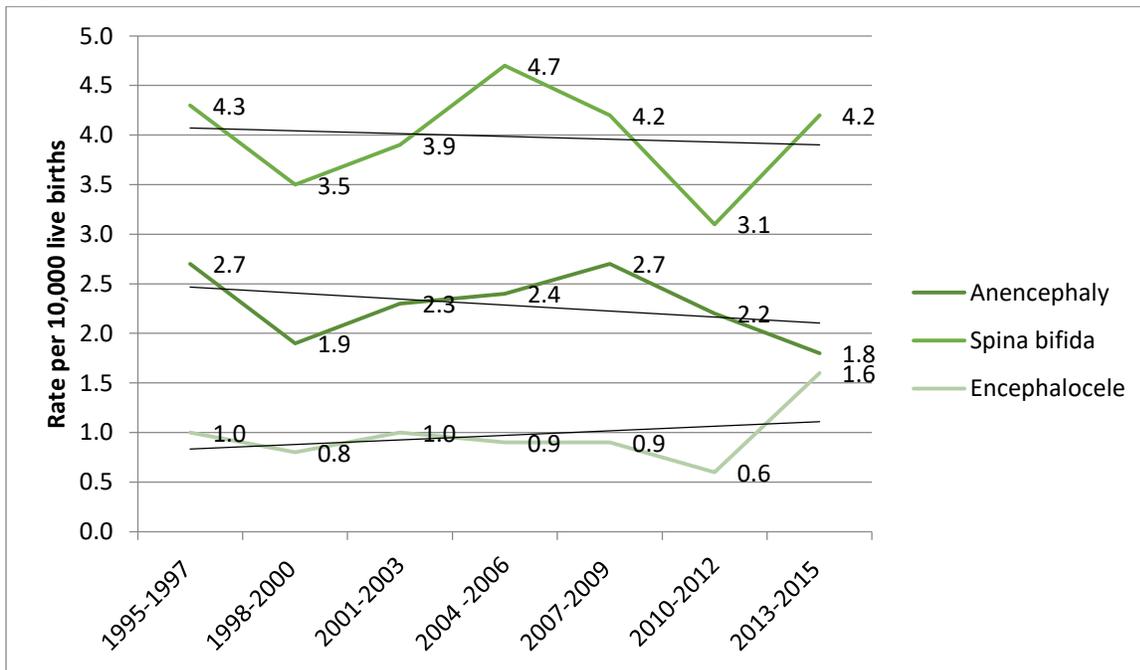
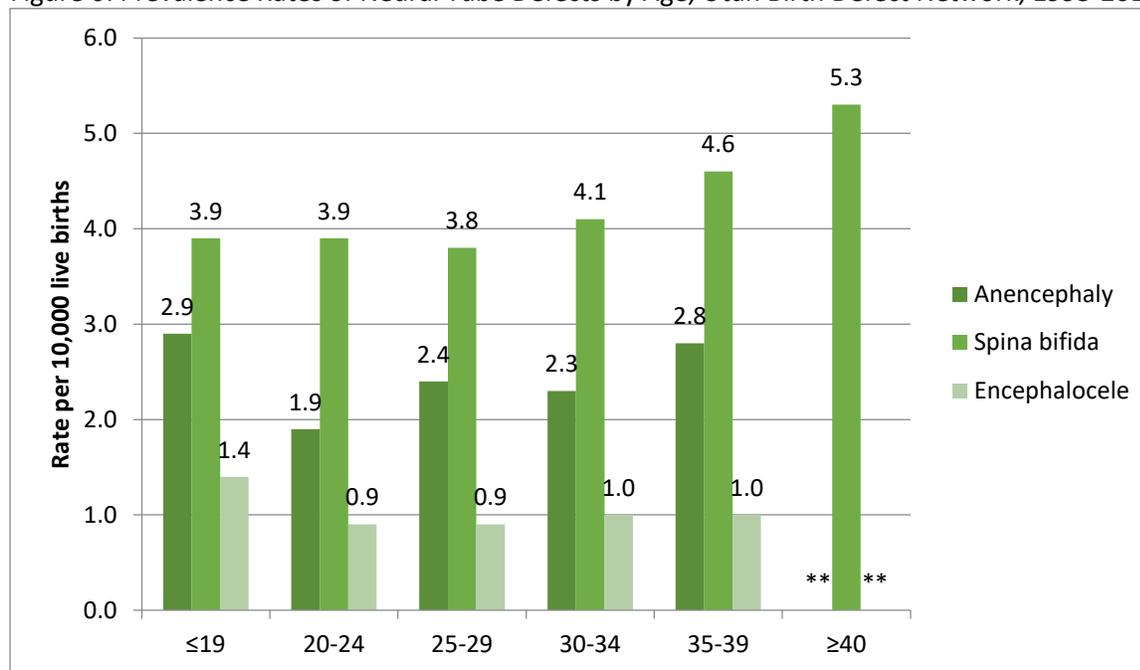
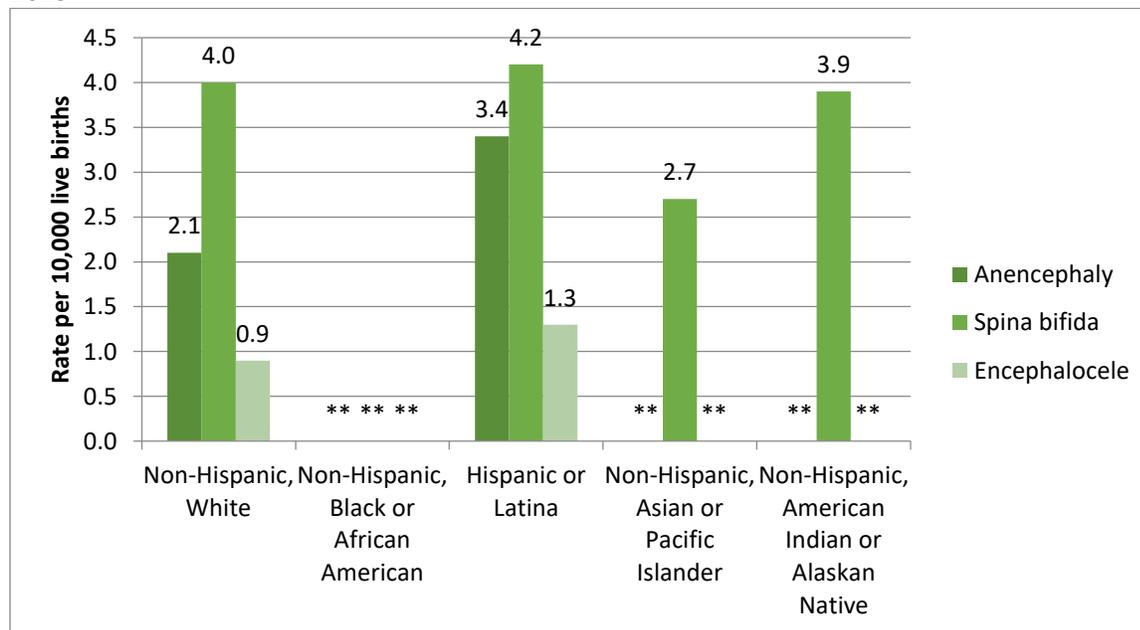


Figure 6: Prevalence Rates of Neural Tube Defects by Age, Utah Birth Defect Network, 1995-2015



\*\*This estimate has been suppressed because 1) The relative standard error is greater than 50% or when the relative standard error can't be determined, 2) the observed number of events is very small and not appropriate for publication, or 3) it could be used to calculate the number in a cell that has been suppressed.

Figure 7: Prevalence Rates of Neural Tube Defects by Race/Ethnicity, Utah Birth Defect Network, 1995-2015



\*\*This estimate has been suppressed because 1) The relative standard error is greater than 50% or when the relative standard error can't be determined, 2) the observed number of events is very small and not appropriate for publication, or 3) it could be used to calculate the number in a cell that has been suppressed.

Figure 8: Prevalence Rates of Neural Tube Defects by Pre-Pregnancy Body Mass Index (BMI), Utah Birth Defect Network, 1995-2015

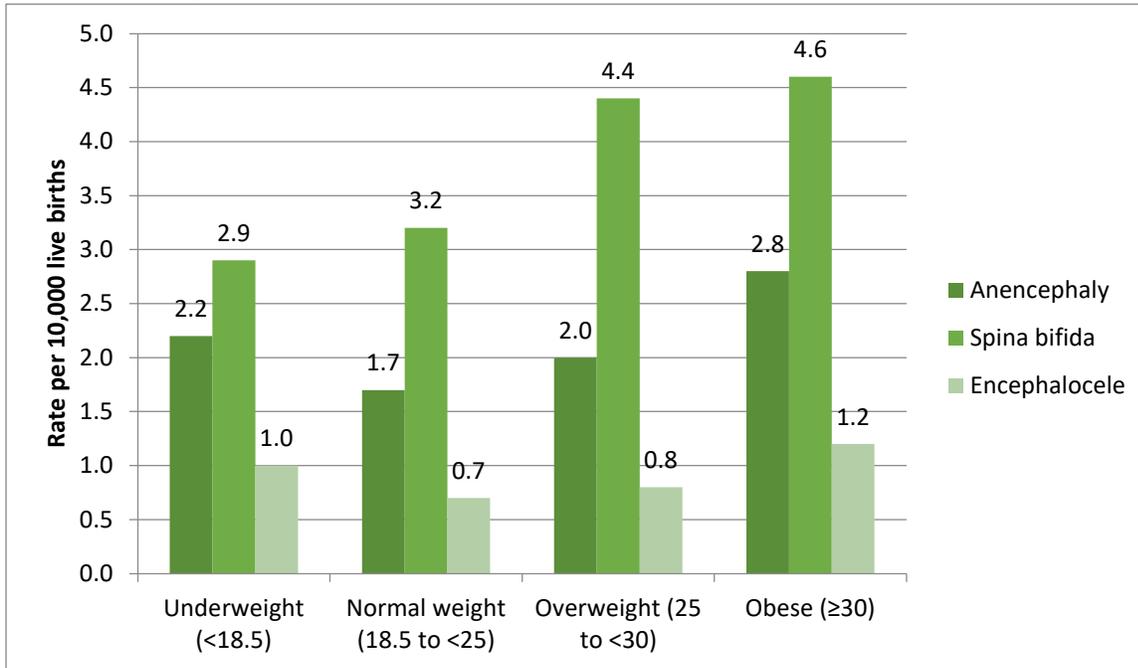
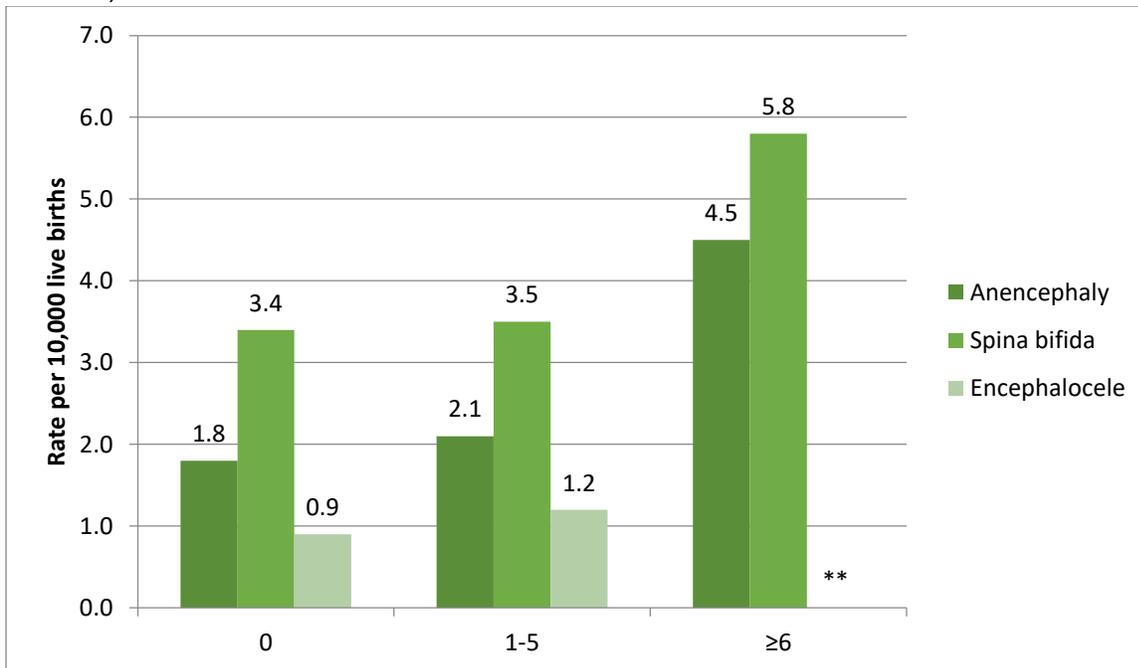
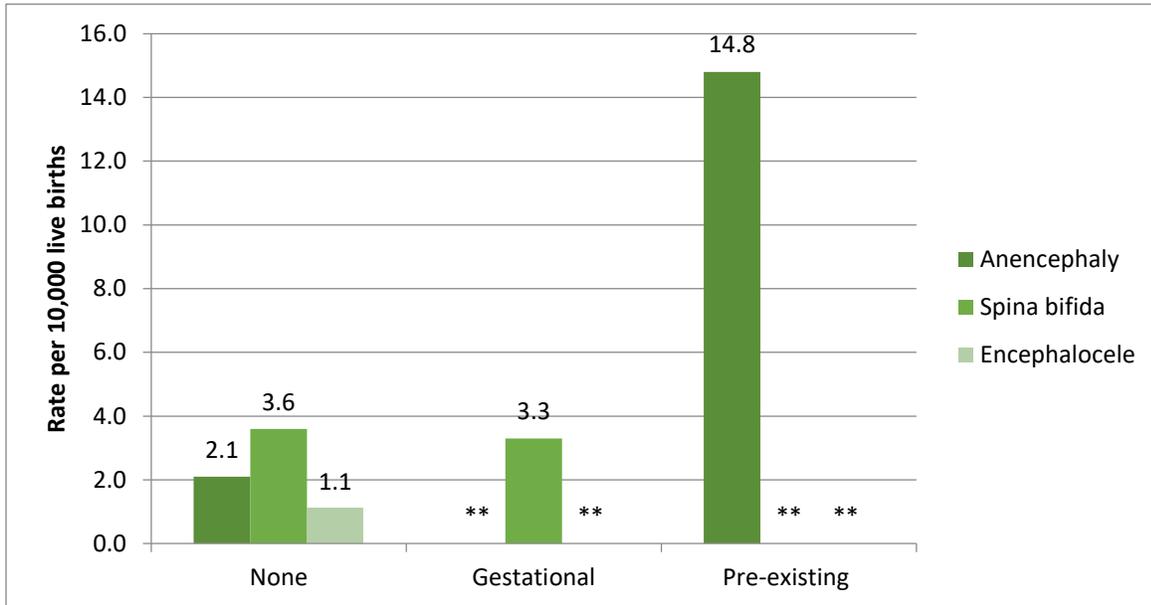


Figure 9: Prevalence Rates of Neural Tube Defects by Number of Previous Pregnancies, Utah Birth Defect Network, 2009-2015



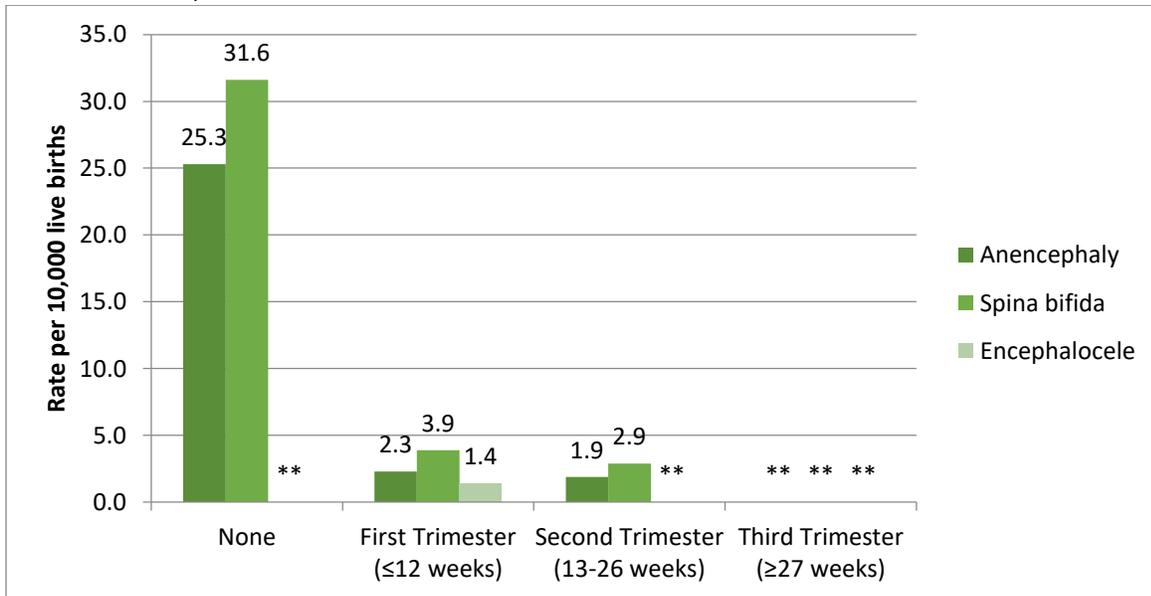
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Figure 10: Prevalence Rates of Neural Tube Defects by Diabetes Status, Utah Birth Defect Network, 2009-2015



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Figure 11: Prevalence Rates of Neural Tube Defects by Trimester of First Prenatal Care Visit, Utah Birth Defect Network, 2009-2015



\*\*This estimate has been suppressed because 1) The relative standard error is greater than 50% or when the relative standard error can't be determined, 2) the observed number of events is very small and not appropriate for publication, or 3) it could be used to calculate the number in a cell that has been suppressed.

Figure 12: Distribution of Folic Acid Awareness among Utah Women Aged 18-44, Utah Behavioral Risk Factor Surveillance System, 2012-2016

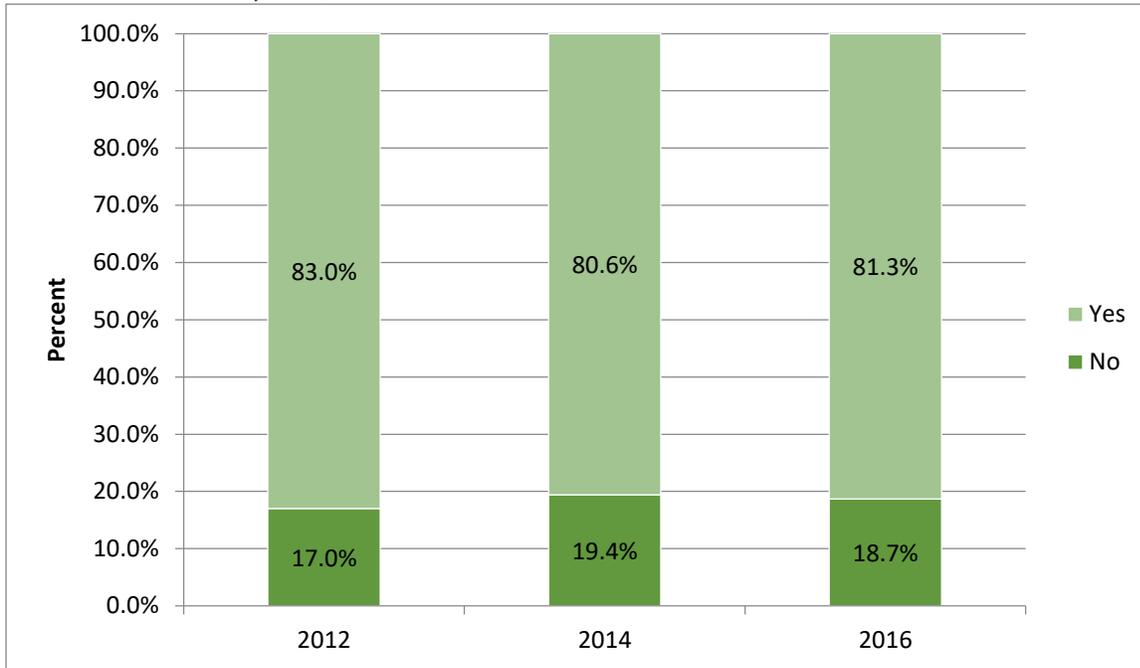


Figure 13: Distribution of Folic Acid Knowledge among Utah Women Aged 18-44, Utah Behavioral Risk Factor Surveillance System, 2012-2016

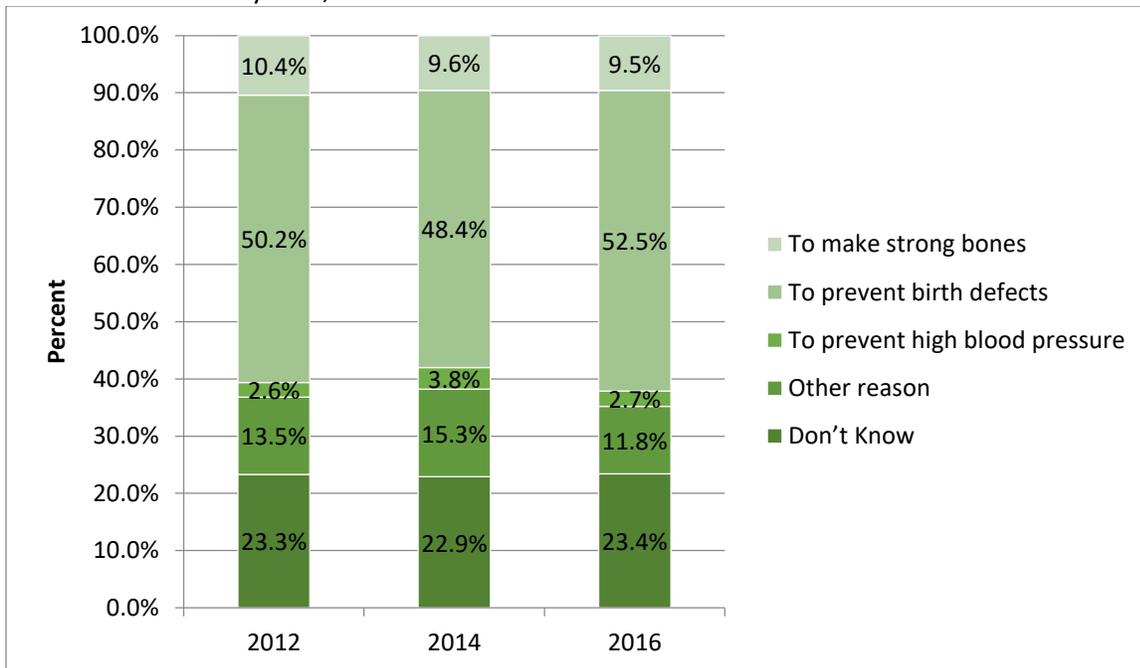
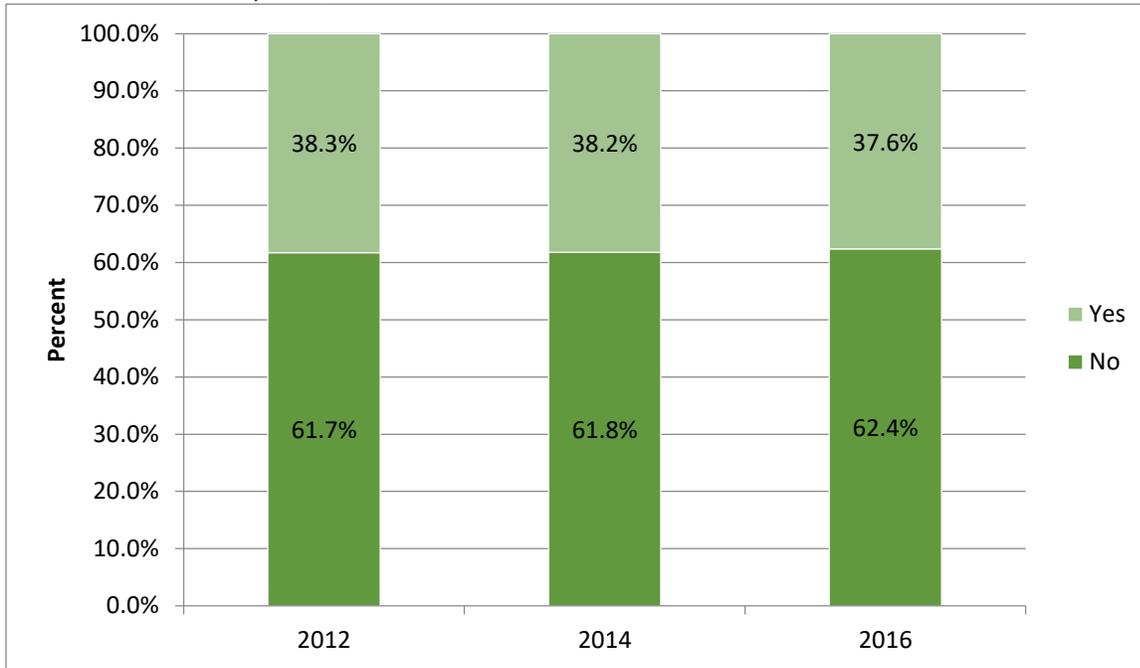


Figure 14: Distribution of Folic Acid Consumption among Utah Women Ages 18-44, Utah Behavioral Risk Factor Surveillance System, 2012-2016



## Tables

Table 3: Distribution by Pregnancy Outcome, Utah Birth Defect Network, 1995-2015

	Count	Percent
<b>Pregnancy Outcome</b>		
Live Birth	469	62.5
Stillbirth	63	8.4
Termination	218	29.1

Note: Live birth = birth where child is born alive; Stillbirth = birth where child has died in the womb after 20 weeks of pregnancy; Termination = elective ending of a pregnancy.

Table 4: Distribution by Isolated/Multiple/Syndromic Status, Utah Birth Defect Network, 1995-2015

	Count	Percent
<b>Isolated/Multiple/Syndromic Status</b>		
Isolated	532	70.9
Multiple	162	21.6
Syndromic	56	7.5

Note: Isolated = has one birth defect; Multiple = has multiple birth defects; Syndromic = has a set of symptoms or signs that make up a recognizable condition of known cause.

Table 5: Prevalence Rates of Neural Tube Defects in Utah, Utah Birth Defect Network, 1995-2015

	Count	Total number of live births	Rate	95% CI LL	95% CI UL
<b>Neural Tube Defect</b>					
Anencephaly	238	1037973	2.3	2.0	2.6
Spina bifida	413	1037973	4.0	3.6	4.4
Encephalocele	100	1037973	1.0	0.8	1.2

Note: Rate = Rate per 10,000 live births, CI = Confidence interval, LL = Lower limit, UL = Upper limit.

Table 6: Prevalence Rates of Anencephaly by Characteristics, Utah Birth Defect Network, 1995-2015

	Count	Total number of live births	Rate per 10,000	95% CI LL	95% CI UL
<b>Year</b>					
1995-1997	34	124619	2.7	1.8	3.6
1998-2000	26	138702	1.9	1.2	2.7
2001-2003	34	146889	2.3	1.5	3.1
2004-2006	38	155645	2.4	1.7	3.2
2007-2009	44	164517	2.7	1.9	3.5
2010-2012	34	154747	2.2	1.5	2.9
2013-2015	28	152854	1.8	1.2	2.6
<b>Age</b>					
≤19	21	72636	2.9	1.8	4.4
20-24	55	288513	1.9	1.4	2.4
25-29	84	348405	2.4	1.9	2.9
30-34	51	224675	2.3	1.6	2.9
35-39	24	86593	2.8	1.8	4.1

≥40**	--	--	--	--	--
<b>Race/Ethnicity</b>					
Non-Hispanic, White	175	829664	2.1	1.8	2.4
Non-Hispanic, Black or African American**	--	--	--	--	--
Hispanic or Latina	50	145138	3.4	2.5	4.4
Non-Hispanic, Asian or Pacific Islander**	--	--	--	--	--
Non-Hispanic, American Indian or Alaskan Native**	--	--	--	--	--
<b>Pre-pregnancy Body Mass Index</b>					
Underweight (<18.5)*	11	50922	2.2	1.1	3.9
Normal weight (18.5 to <25)	100	588146	1.7	1.4	2.0
Overweight (25 to <30)	42	212012	2.0	1.4	2.6
Obese (≥30)	44	155382	2.8	2.0	3.7
<b>Number of Previous Pregnancies</b>					
0	18	99126	1.8	1.1	2.9
1-5	53	246868	2.1	1.6	2.7
≥6*	7	15454	4.5	1.8	9.3
<b>Diabetes Status</b>					
None	72	343370	2.1	1.6	2.6
Gestational**	--	--	--	--	--
Pre-existing *	4	2699	14.8	4.0	37.9
<b>Trimester of First Prenatal Care Visit</b>					
None*	4	1583	25.3	6.9	64.7
First Trimester (≤12 weeks)	62	270448	2.3	1.7	2.9
Second Trimester (13-26 weeks)	12	61573	1.9	1.0	3.4
Third Trimester (≥27 weeks)**	--	--	--	--	--

Note: Rate = Rate per 10,000 live births, CI = Confidence interval, LL = Lower limit, UL = Upper limit.

Rates for number of previous pregnancies, diabetes status, and trimester of first prenatal care visit were restricted to data from 2009-2015.

\*Use caution in interpreting, the estimate has a relative standard error greater than 30% and does not meet UDOH standards for reliability.

\*\*This estimate has been suppressed because 1) The relative standard error is greater than 50% or when the relative standard error can't be determined, 2) the observed number of events is very small and not appropriate for publication, or 3) it could be used to calculate the number in a cell that has been suppressed.

Table 7: Prevalence Rates of Spina Bifida by Characteristics, Utah Birth Defect Network, 1995-2015

	Count	Total number of live births	Rate per 10,000	95% CI LL	95% CI UL
<b>Year</b>					
1995-1997	53	124619	4.3	3.1	5.4
1998-2000	49	138702	3.5	2.5	4.5
2001-2003	57	146889	3.9	2.9	4.9
2004-2006	73	155645	4.7	3.6	5.8
2007-2009	69	164517	4.2	3.2	5.2

2010-2012	48	154747	3.1	2.2	4.0
2013-2015	64	152854	4.2	3.2	5.2
<b>Age</b>					
≤19	28	72636	3.9	2.6	5.6
20-24	113	288513	3.9	3.2	4.6
25-29	132	348405	3.8	3.1	4.4
30-34	91	224675	4.1	3.2	4.9
35-39	40	86593	4.6	3.2	6.1
≥40*	9	17025	5.3	2.4	10.0
<b>Race/Ethnicity</b>					
Non-Hispanic, White	333	829664	4.0	3.6	4.4
Non-Hispanic, Black or African American**	--	--	--	--	--
Hispanic or Latina	61	145138	4.2	3.1	5.3
Non-Hispanic, Asian or Pacific Islander*	7	26371	2.7	1.1	5.5
Non-Hispanic, American Indian or Alaskan Native*	5	12821	3.9	1.3	9.1
<b>Pre-pregnancy Body Mass Index</b>					
Underweight (<18.5)	15	50922	2.9	1.6	4.9
Normal weight (18.5 to <25)	188	588146	3.2	2.7	3.7
Overweight (25 to <30)	93	212012	4.4	3.5	5.3
Obese (≥30)	72	155382	4.6	3.6	5.7
<b>Number of Previous Pregnancies</b>					
0	34	99126	3.4	2.3	4.6
1-5	86	246868	3.5	2.7	4.2
≥6*	9	15454	5.8	2.7	11.1
<b>Diabetes Status</b>					
None	123	343370	3.6	2.9	4.2
Gestational*	5	15380	3.3	1.1	7.6
Pre-existing **	--	--	--	--	--
<b>Trimester of First Prenatal Care Visit</b>					
None*	5	1583	31.6	10.2	73.7
First Trimester (≤12 weeks)	105	270448	3.9	3.1	4.6
Second Trimester (13-26 weeks)	18	61573	2.9	1.7	4.6
Third Trimester (≥27 weeks)**	--	--	--	--	--

Note: Rate = Rate per 10,000 live births, CI = Confidence interval, LL = Lower limit, UL = Upper limit.

Rates for number of previous pregnancies, diabetes status, and trimester of first prenatal care visit were restricted to data from 2009-2015.

\*Use caution in interpreting, the estimate has a relative standard error greater than 30% and does not meet UDOH standards for reliability.

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Table 8: Prevalence Rates of Encephalocele by Characteristics, Utah Birth Defect Network, 1995-2015

	Count	Total number of live births	Rate per 10,000	95% CI LL	95% CI UL
<b>Year</b>					
1995-1997	12	124619	1.0	0.5	1.7
1998-2000*	11	138702	0.8	0.4	1.4
2001-2003	14	146889	1.0	0.5	1.6
2004-2006	14	155645	0.9	0.5	1.5
2007-2009	15	164517	0.9	0.5	1.5
2010-2012*	10	154747	0.6	0.3	1.2
2013-2015	24	152854	1.6	1.0	2.3
<b>Age</b>					
≤19*	10	72636	1.4	0.7	2.5
20-24	25	288513	0.9	0.6	1.3
25-29	30	348405	0.9	0.6	1.2
30-34	23	224675	1.0	0.6	1.5
35-39*	9	86593	1.0	0.5	2.0
≥40**	--	--	--	--	--
<b>Race/Ethnicity</b>					
Non-Hispanic, White	76	829664	0.9	0.7	1.1
Non-Hispanic, Black or African American**	--	--	--	--	--
Hispanic or Latina	19	145138	1.3	0.8	2.0
Non-Hispanic, Asian or Pacific Islander**	--	--	--	--	--
Non-Hispanic, American Indian or Alaskan Native**	--	--	--	--	--
<b>Pre-pregnancy Body Mass Index</b>					
Underweight (<18.5)*	5	50922	1.0	0.3	2.3
Normal weight (18.5 to <25)	41	588146	0.7	0.5	0.9
Overweight (25 to <30)	16	212012	0.8	0.4	1.2
Obese (≥30)	18	155382	1.2	0.7	1.8
<b>Number of Previous Pregnancies</b>					
0*	9	99126	0.9	0.4	1.7
1-5	29	246868	1.2	0.8	1.7
≥6**	--	--	--	--	--
<b>Diabetes Status</b>					
None	38	343370	1.1	0.8	1.5
Gestational**	--	--	--	--	--
Pre-existing**	--	--	--	--	--
<b>Trimester of First Prenatal Care Visit</b>					
None**	--	--	--	--	--
First Trimester (≤12 weeks)	38	270448	1.4	1.0	1.9

Second Trimester (13-26 weeks)**	--	--	--	--	--
Third Trimester (≥27 weeks)**	--	--	--	--	--

Note: Rate = Rate per 10,000 live births, CI = Confidence interval, LL = Lower limit, UL = Upper limit.

Rates for number of previous pregnancies, diabetes status, and trimester of first prenatal care visit were restricted to data from 2009-2015.

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Table 9: Folic Acid Awareness among Utah Women Aged 18 -44, Utah Behavioral Risk Factor Surveillance System, 2012-2016

	Yes	No
Year	Percent	Percent
2012	83.0	17.0
2014	80.6	19.4
2016	81.3	18.7

Table 10: Folic Acid Knowledge among Utah Women Aged 18-44, Utah Behavioral Risk Factor Surveillance System, 2012-2016

	To make strong bones	To prevent birth defects	To prevent high blood pressure	Other reason	Don't Know
Year	Percent	Percent	Percent	Percent	Percent
2012	10.4	50.2	2.6	13.5	23.3
2014	9.6	48.4	3.8	15.3	22.9
2016	9.5	52.5	2.7	11.8	23.4

Table 11: Folic Acid Consumption among Utah Women Ages 18-44, Utah Behavioral Risk Factor Surveillance System, 2012-2016

	Yes	No
Year	Percent	Percent
2012	38.3	61.7
2014	38.2	61.8
2016	37.6	62.4

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