



Anencephaly in Central Washington: Investigation Findings, Ongoing Surveillance and Prevention Activities

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HEALTHIER COMMUNITY



What is Anencephaly?

- Type of neural tube birth defect
- Results from the failure of the neural tube to close in the cranial region by the 28th day of gestation
- Infants with anencephaly die shortly after birth
- Other neural tube defects include spina bifida and encephalocele

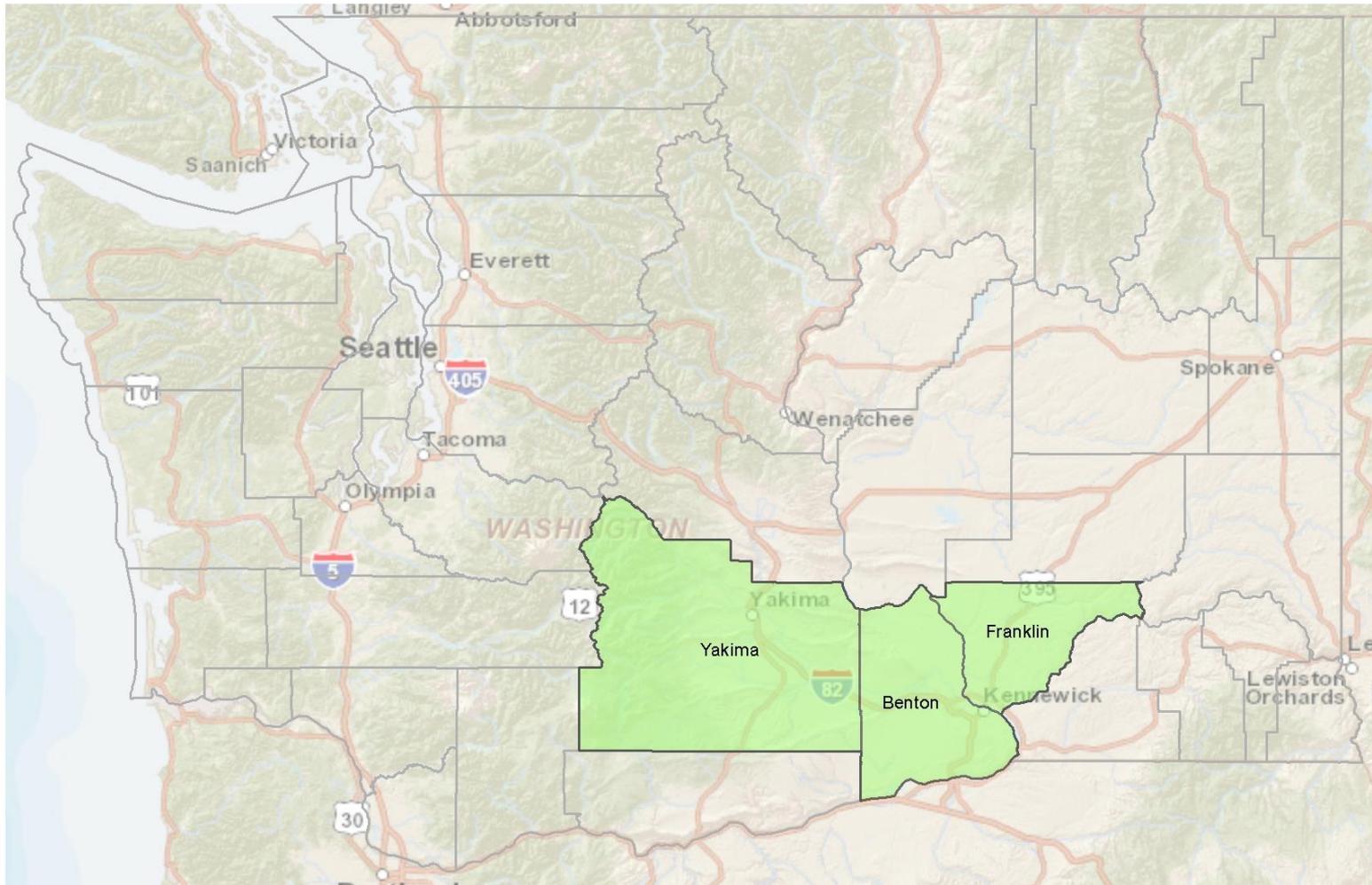
Risk Factors for Neural Tube Defects (NTDs)

- Folic acid insufficiency
- Obesity
- Diabetes
- Hispanic Ethnicity
- Selected medications
- Previous neural tube defect-affected pregnancy
- Hyperthermia

Background of Investigation

- In August 2012, Department of Health (DOH) alerted by healthcare provider about several infants born with anencephaly in central Washington
- Examined referral patterns for high-risk pregnancies
- Defined investigation area as Yakima, Benton, and Franklin counties
- Contacted Centers for Disease Control and Prevention (CDC) for technical assistance
- Performed active surveillance November 2012

Investigation Area



Case Definition

- ICD-9 code: 740, 741, 742, 655.0
- Confirmed diagnosis: ultrasound, pathology report, or physical examination
- Resident: Yakima, Benton, or Franklin counties at time of conception
- Last menstrual period: August 2009 – present

Active Surveillance

- Searched hospital records including billing records with discharge codes, labor and delivery logs, newborn and fetal deaths
- Searched birth, death, and fetal death vital statistics records
- Requested perinatology records
- Reviewed medical records of all suspect cases to validate the diagnosis

Initial Findings

- 27 cases of NTD from January 2010 – January 2013:
 - 23 anencephaly, 3 spina bifida, 1 encephalocele
- Rates:
 - Anencephaly: 8.4/10,000 vs US 2.1/10,000*
 - Spina bifida: 1.3/10,000 vs US 3.5/10,000*

*Parker SE, 2010

Medical Records Study

- Case-control study (27 cases, 108 controls)
- Medical records abstraction of data:
 - demographics, pregnancy history, pregnancy conditions, medications, substance use, residential address
- Vital Statistics data when available
- Parcel data from county tax assessor to establish public or private water systems
- Water quality data to examine nitrate levels in public water system

Medical Records Study Conclusions

- No clear associations nor exposures affecting large proportion of cases
- No statistically significant differences between cases and controls, although study had low power
- Overall low early pregnancy folic acid use in both case and control groups
- PRAMS Survey data 2009 – 2011:
 - 61% no early pregnancy folic acid 3-county area
 - 50% in the rest of Washington State

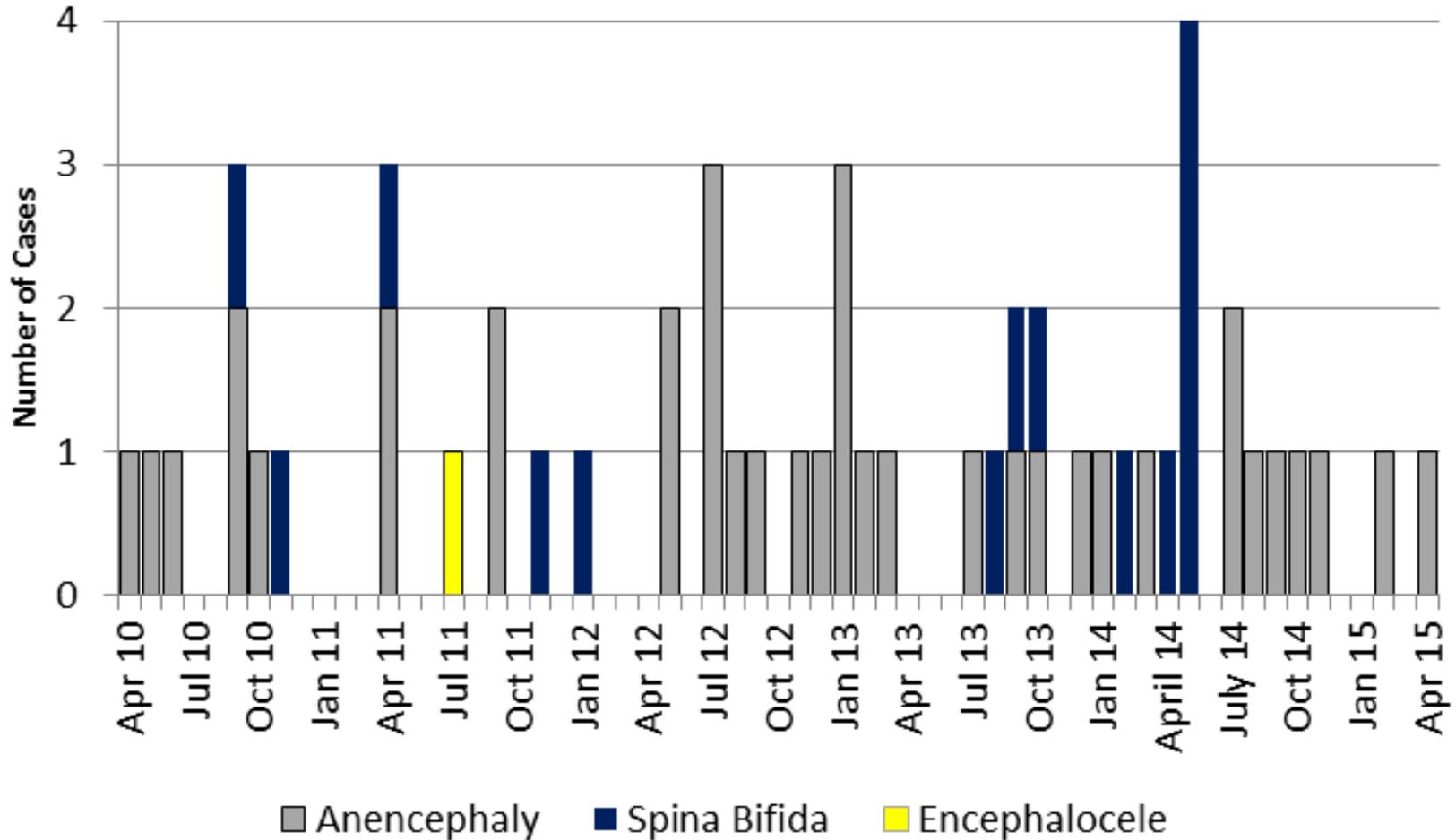
Neural Tube Defects by Year of Delivery or Estimated Year of Delivery¹

	Number	Total births	Rate per 10,000 births	95% CI
All Neural Tube Defects				
2010	8	8565	9.3	(4.0, 18.4)
2011	7	8528	8.2	(3.3, 16.9)
2012	10	8352	12.0	(5.7, 22.0)
2013	12	8084	14.8	(7.7, 25.9)
2014	14	na		
2015	2	na		
Total to date ²	53	na		
Anencephaly				
2010	6	8565	7.0	(2.6, 15.2)
2011	4	8528	4.7	(1.3, 12.0)
2012	9	8352	10.8	(4.9, 20.5)
2013	9	8084	11.1	(5.1, 21.1)
2014	8	na		
2015	2	na		
Total to date ²	38	na		

¹Estimated year of delivery is used for cases terminated or delivered before 37 weeks gestation.

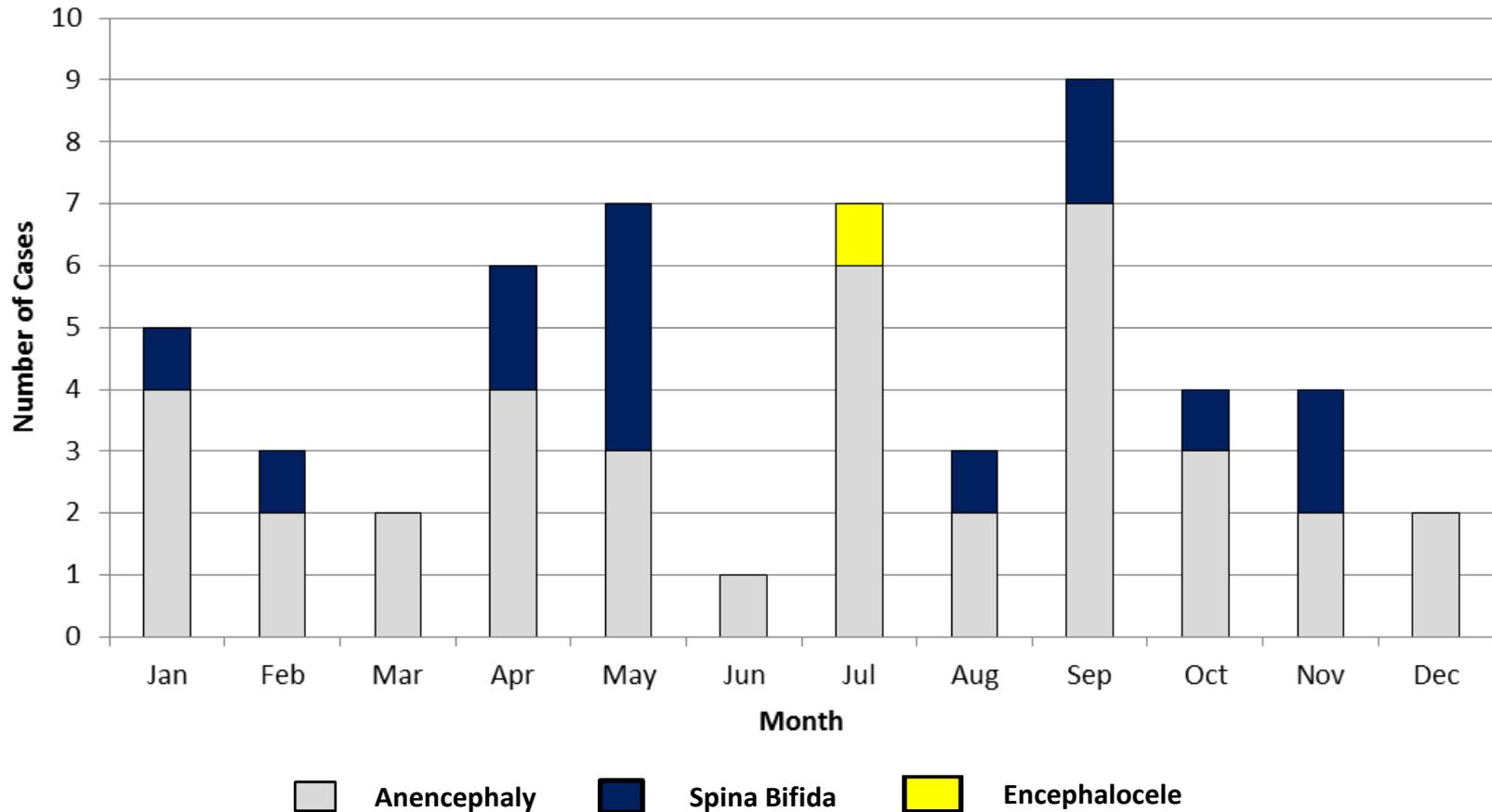
²Total to date reflects cases confirmed by January 9, 2015 with a delivery or estimated date of delivery in 2010-2015.

Neural Tube Defects by Month of Estimated Delivery Date¹



¹Estimated delivery date uses delivery date for gestational age ≥ 37 weeks and estimated delivery date for gestational age <37 weeks at delivery. Cases were confirmed through January 9, 2015.

Neural Tube Defects by Month of Estimated Delivery Date 2010-2015 Combined¹



¹Estimated delivery date uses delivery date for gestational age ≥ 37 weeks and estimated delivery date for gestational age <37 weeks at delivery. Cases were confirmed through January 9, 2015.

Neural Tube Defects by County of Residence¹

	Total Number ¹	Number 2010-2013	2010-2013 births	Rate per 10,000 births	95% CI
All Neural Tube Defects					
Benton County	20	14	10,171	13.8	(7.5, 23.1)
Franklin County	9	7	6,698	10.5	(4.2, 21.5)
Yakima County	24	16	16,660	9.6	(5.5, 15.6)
3 County Area	53	37	33,529	11.0	(7.5, 15.2)
Anencephaly					
Benton County	15	13	10,171	12.8	(6.8, 21.9)
Franklin County	6	4	6,698	6.0	(1.6, 15.3)
Yakima County	17	11	16,660	6.6	(3.3, 11.8)
3 County Area	38	28	33,529	8.4	(5.5, 12.1)

¹Total number reflects cases confirmed by January 9, 2015 with a delivery or estimated date of delivery in 2010-2015.

Neural Tube Defects by Geography

- We have a map, but are not sharing it to protect the mothers' confidentiality
- Mothers with affected pregnancies resided across the 3-county area
- Case mothers resided in 16 of the 33 zip codes in the 3-county area
- In general, more cases from more populated areas

Neural Tube Defects by Race Ethnicity

	Total Number ¹	Number 2010-2013	2010-2013 births	Rate per 10,000 births	95% CI
All Neural Tube Defects					
Hispanic	24	18	17,435	10.3	(6.1, 16.3)
Non-Hispanic White	22	16	13,559	11.8	(6.7, 19.2)
Other	1	0	2,535	0.0	
Anencephaly					
Hispanic	19	15	17,435	8.6	(4.8, 14.2)
Non-Hispanic White	13	10	13,559	7.4	(3.5, 13.6)
Other	0	0	2,535	0.0	

¹Total number reflects cases confirmed by January 9, 2015 with a delivery or estimated date of delivery in 2010-2015. Six anencephaly cases had unknown race/ethnicity.

Washington Rates of Anencephaly and Spina Bifida¹

	Anencephaly	Rate per 10,000	All Neural Tube Defects	Rate per 10,000	Births
2005	18	2.2	39	4.7	82,625
2006	13	1.5	45	5.2	86,845
2007	21	2.4	55	6.2	88,921
2008	24	2.7	59	6.5	90,270
2009	25	2.8	55	6.2	89,242
2010	27	3.1	53	6.1	86,480
2011	35	4.0	64	7.4	86,929
2012	23	2.6	49	5.6	87,417
2005-2012	186	2.7	419	6.0	698,729

¹Based on ascertainment from birth certificates, fetal death certificates and hospital discharge data.

Advisory Committee

- Susie Ball – Central Washington Genetics Counselor
- Sara Barron – Community Member
- Jessica Black – Professor Environmental Science, Heritage University
- Nora Coronado – Washington State Committee on Hispanic Affairs
- Lisa Galbraith – Kadlec Clinic OB/GYN
- Phil Halvorsen – Perinatal Center-Richland
- Marie Jennings – Manager Drinking Water Unit, US EPA-Region 10
- Peter Langlois – Birth Defects Epidemiology, Texas Department of State Health Services
- Gina Legaz – Washington Chapter March of Dimes
- Kathy Lofy – State Health Officer, Washington State Department of Health – Chair
- Jennie McLaurin – Migrant Clinicians Network
- Richard S. Olney – National Center Birth Defects, CDC
- Amy Person – Health Officer, Benton Franklin Health District
- Kathleen Rogers – Community Member
- Melissa Schiff – Professor Epidemiology, University of Washington
- Chris Spitters – Health Officer, Yakima Health District
- Vickie Ybarra – Community Member

Advisory Committee Goals

Surveillance: Identify ways to improve reporting of neural tube defects to better ascertain rates of occurrence

Investigation: Determine if additional investigation should be conducted to assess potential exposures, and what specifically is recommended as next steps

Prevention: Identify actions to prevent or reduce the likelihood of neural tube defects in the area

Surveillance Plan

- Ongoing identification of neural tube defects in 3-county area using stimulated passive surveillance from hospitals and providers with active follow up by Washington State Department of Health
- Ongoing statewide passive surveillance using vital statistics and linked files
- Quarterly reporting through July 2015

Surveillance Options

Surveillance Type	States Using	LB/FD/Term	Strengths	Annual Cost (for 90,000 births)
Passive	13	Livebirths Fetal Deaths Term > 20 wks	Easy to collect Relatively inexpensive	\$90,000–\$450,000
Passive with Active Follow Up	20	Livebirths Fetal Deaths Terms > 20 wks	More complete case ascertainment Can focus on selected conditions, geography and/or facilities for follow up	\$450,000–\$900,000
Active Surveillance	10	Livebirths Fetal Deaths All Terms	Complete ascertainment Can collect risk factor data from charts/logs	\$900,000–\$2,700,000

Investigation Plan

- Conduct phone interviews of mothers of infants with neural tube defects in 3-county area using National Birth Defects Prevention Study questionnaire
- This will ensure we have not overlooked a common exposure
- Questionnaire covers maternal health, pregnancy history, nutrition, substance use, demographics, water use, occupation, and residence history
- Plan to approach 25 mothers

Prevention Plan – Messages

- Recommend that all women of childbearing age take 400 micrograms of folic acid daily
- Recommend women of childbearing age on private well water test water annually for bacteria and nitrates
- Promote preconception health
- Encourage pregnant women to seek early prenatal care

Prevention – Provider Outreach

- Local health communication to providers via blast fax and newsletters
- Presentations:
 - Grand Rounds
 - Trainings
 - Conferences
- Exploring development of materials for providers to encourage folic acid use by all women of reproductive age

Prevention – Public Outreach

- Public Service radio spots and banner ads in English and Spanish – March of Dimes
- Brochure distribution
- Hispanic Health Commission/Department of Health radio programming
- Department of Health web pages – anencephaly and women's health

Prevention – Folic Acid

- Monitoring national effort to supplement corn masa flour with folic acid
- Investigating subsidized folic acid vitamin use

Ongoing Efforts

- Advisory Committee meetings every 6-8 weeks
 - Update on investigation
 - Quarterly update of data
 - Prevention efforts
- Monthly prevention coordination call
- Continued presentations to providers and public
- Ongoing response to media inquiries

To provide comments or questions,
please contact:

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