



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

Governor's Interagency Council on Health Disparities  
February 11, 2015

Cathy Wasserman, PhD, State Epidemiologist for Non-Infectious Conditions



# 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 28<sup>th</sup> day of gestation
- Infants with anencephaly die shortly after birth
- Other neural tube defects include spina bifida and encephalocele

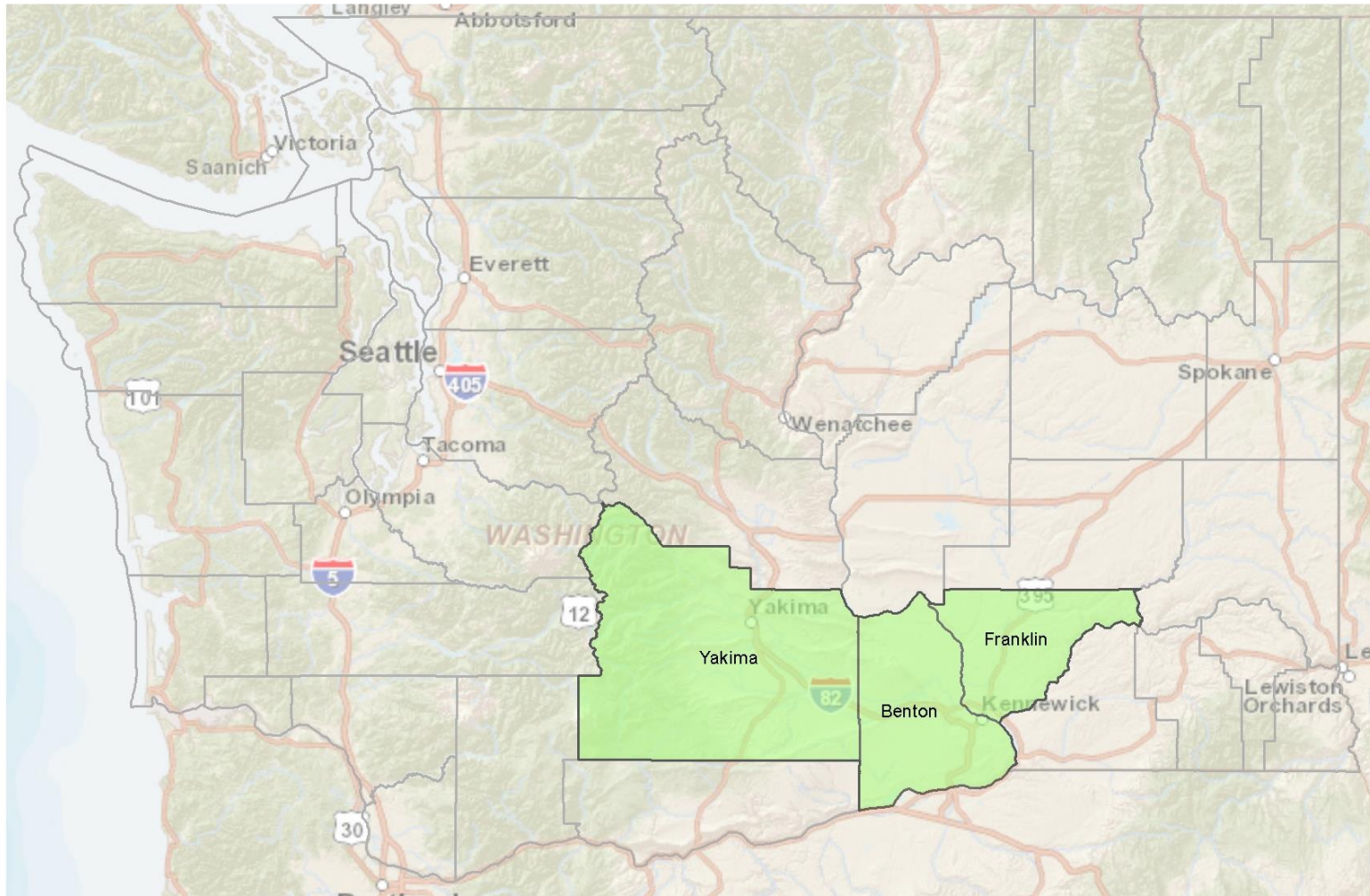
# Risk Factors for Neural Tube Defects (NTDs)

- 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

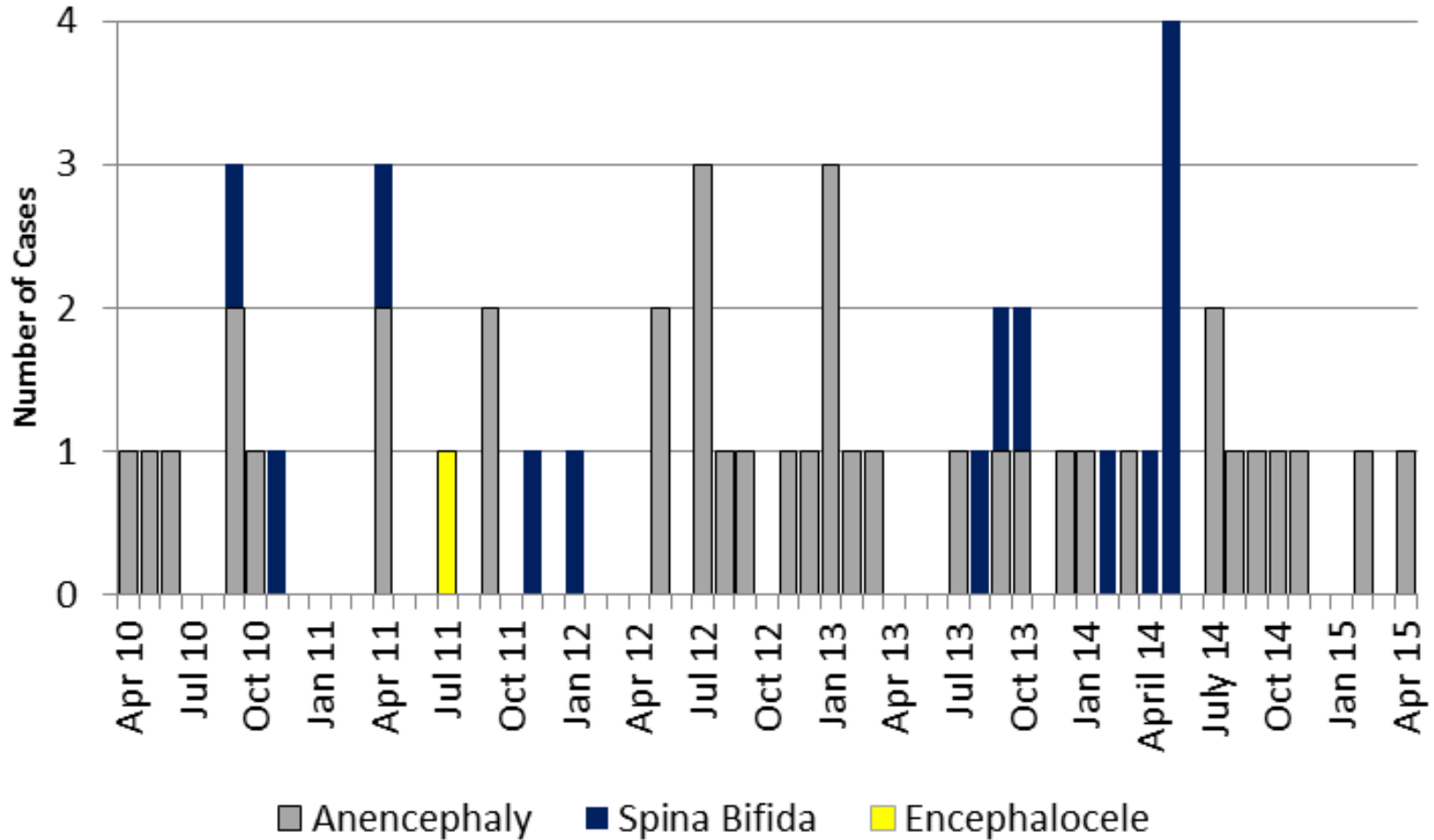
# Neural Tube Defects by Year of Delivery or Estimated Year of Delivery<sup>1</sup>

|                                | Number | Total births | Rate per 10,000 births | 95% CI      |
|--------------------------------|--------|--------------|------------------------|-------------|
| <b>All Neural Tube Defects</b> |        |              |                        |             |
| 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 <sup>2</sup>     | 53     | na           |                        |             |
| <b>Anencephaly</b>             |        |              |                        |             |
| 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 <sup>2</sup>     | 38     | na           |                        |             |

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

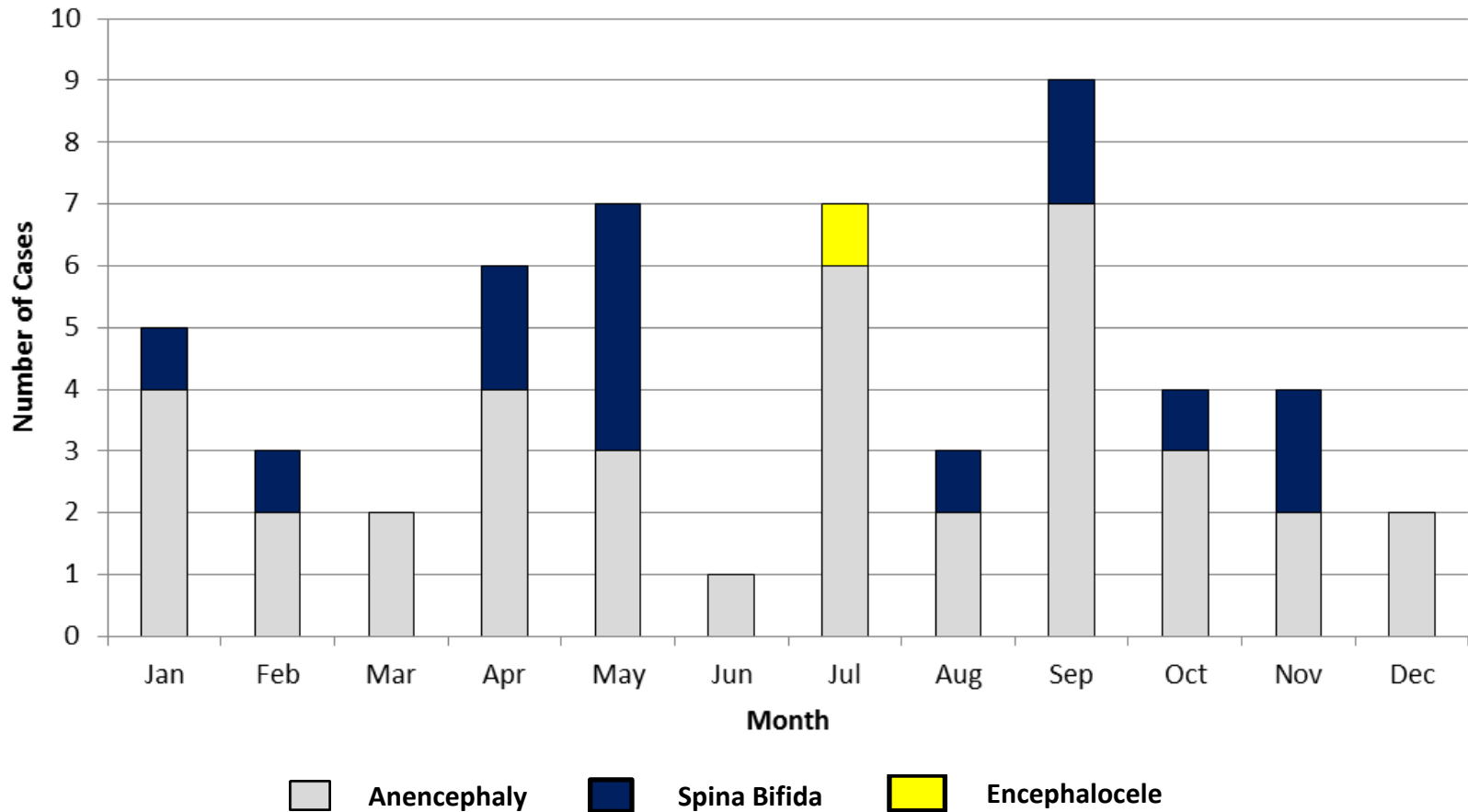
<sup>2</sup>Total to date reflects cases confirmed by January 9, 2015 with a delivery or estimated date of delivery in 2010-2015.

# Neural Tube Defects by Month of Estimated Delivery Date<sup>1</sup>



<sup>1</sup>Estimated delivery date uses delivery date for gestational age  $\geq 37$  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 Combined<sup>1</sup>



<sup>1</sup>Estimated delivery date uses delivery date for gestational age  $\geq 37$  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 Residence<sup>1</sup>

|                                | Total Number <sup>1</sup> | Number 2010-2013 | 2010-2013 births | Rate per 10,000 births | 95% CI      |
|--------------------------------|---------------------------|------------------|------------------|------------------------|-------------|
| <b>All Neural Tube Defects</b> |                           |                  |                  |                        |             |
| 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) |
| <b>Anencephaly</b>             |                           |                  |                  |                        |             |
| 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) |

<sup>1</sup>Total 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 <sup>1</sup> | Number 2010-2013 | 2010-2013 births | Rate per 10,000 births | 95% CI      |
|--------------------------------|---------------------------|------------------|------------------|------------------------|-------------|
| <b>All Neural Tube Defects</b> |                           |                  |                  |                        |             |
| 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                    |             |
| <b>Anencephaly</b>             |                           |                  |                  |                        |             |
| 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                    |             |

<sup>1</sup>Total 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 Bifida<sup>1</sup>

|                   | <b>Anencephaly</b> | <b>Rate per 10,000</b> | <b>All Neural Tube Defects</b> | <b>Rate per 10,000</b> | <b>Births</b> |
|-------------------|--------------------|------------------------|--------------------------------|------------------------|---------------|
| 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        |
| 2013 <sup>2</sup> | 22                 | 2.5                    | 42                             | 4.9                    | 86,566        |
| 2005-2013         | 208                | 2.6                    | 461                            | 5.9                    | 785,295       |

<sup>1</sup>Based on ascertainment from birth certificates, fetal death certificates and hospital discharge data, 2005-2012 .

<sup>2</sup>Based on ascertainment from birth certificates and fetal death certificates only, 2013.

# Washington Rates of Anencephaly and Spina Bifida<sup>1</sup>

|                                | Number<br>2005-2012 | 2005-2012<br>births | Rate per<br>10,000 births | 95% CI      |
|--------------------------------|---------------------|---------------------|---------------------------|-------------|
| <b>All Neural Tube Defects</b> |                     |                     |                           |             |
| 3 County Area                  | 59                  | 67,287              | 8.8                       | (6.7, 11.3) |
| Rest of Washington             | 360                 | 631,442             | 5.7                       | (5.1, 6.3)  |
| Total Washington               | 419                 | 698,729             | 6.0                       | (5.4, 6.6)  |
| <b>Anencephaly</b>             |                     |                     |                           |             |
| 3 County Area                  | 36                  | 67,287              | 5.4                       | (3.7, 7.4)  |
| Rest of Washington             | 150                 | 631,442             | 2.4                       | (2.0, 2.8)  |
| Total Washington               | 186                 | 698,729             | 2.7                       | (2.3, 3.1)  |

<sup>1</sup>Based on ascertainment from birth certificates, fetal death certificates and hospital discharge data, 2005-2012 .

# 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

# 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:

Cathy Wasserman, PhD MPH

State Epidemiologist for Non-Infectious Conditions

Washington State Department of Health

PO Box 47890

Olympia, WA 98504-7890

[cathy.wasserman@doh.wa.gov](mailto:cathy.wasserman@doh.wa.gov)