



# Anencephaly Investigation

Central Washington, 2010-2016

Advisory Committee Meeting  
August

23, 2016

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

**PUBLIC HEALTH**  
ALWAYS WORKING FOR A SAFER AND  
**HEALTHIER COMMUNITY**



# Surveillance Update

# 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	9	8565	10.5	(4.8, 19.9)
2011	8	8528	9.4	(4.0, 18.5)
2012	10	8352	12.0	(5.7, 22.0)
2013	14	8084	17.3	(9.5, 29.1)
2014	14	8432	16.6	(9.1, 27.9)
2015	9	8332	10.8	(4.9, 20.5)
2016	4	N/A	.	.
2017	1	N/A	.	.
Total to date <sup>2</sup>	69	.	.	.
<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	8432	9.5	(4.1, 18.7)
2015	5	8332	6.0	(2.0, 14.0)
2016	2	N/A	.	.
2017	1	N/A	.	.
Total to date <sup>2</sup>	44	.	.	.

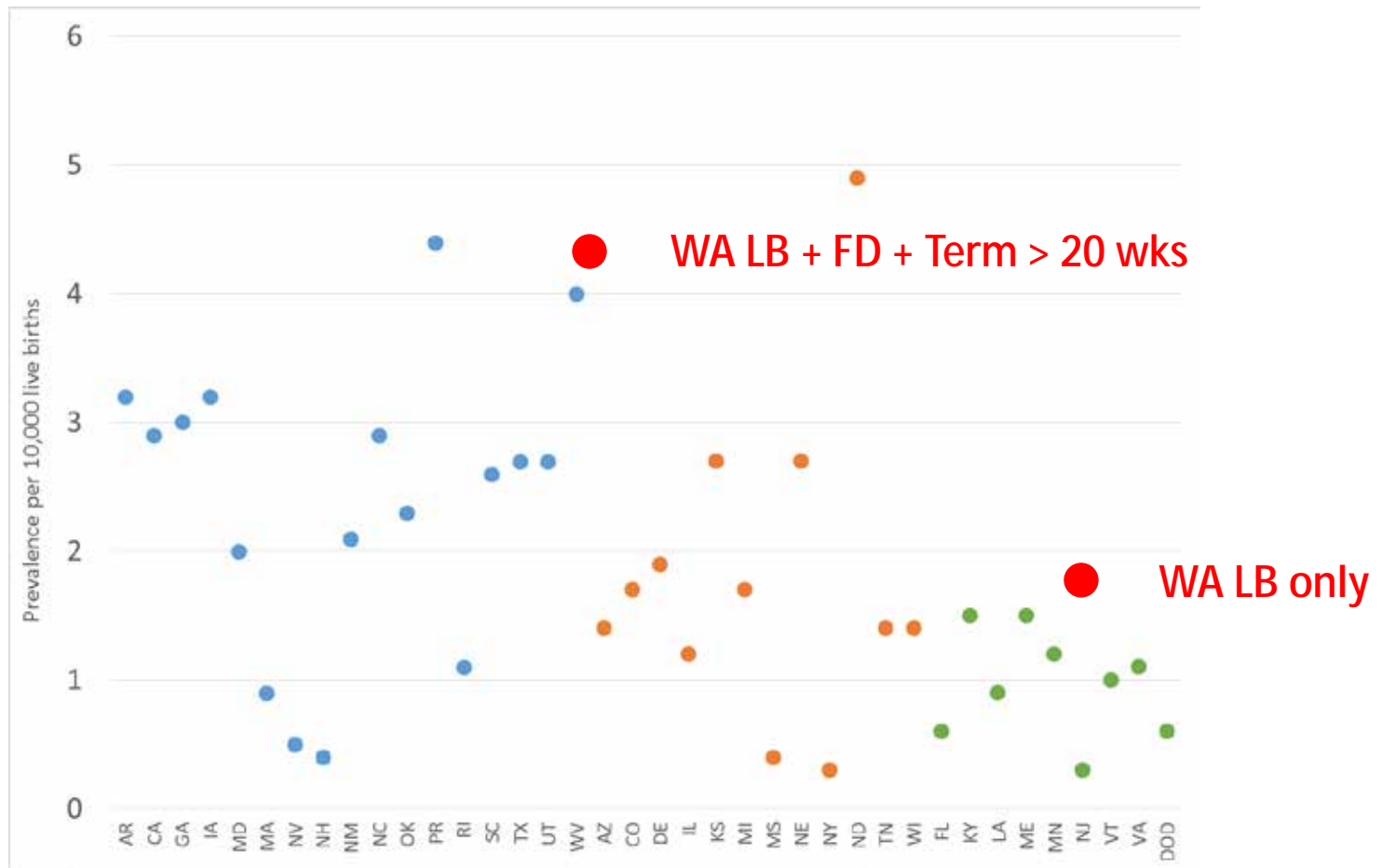
<sup>1</sup>Estimated year of delivery is used for cases terminated or delivered before 37 weeks gestation.

<sup>2</sup>Total to date reflects cases confirmed by July 15, 2016 with a delivery or estimated date of delivery in 2010-2017.

WA Total =  
8.2

# Prevalence of Anencephaly, 2007-2011

## National Birth Defects Prevention Network



Live births, terminations and stillbirths



Live births and stillbirths



Live births only

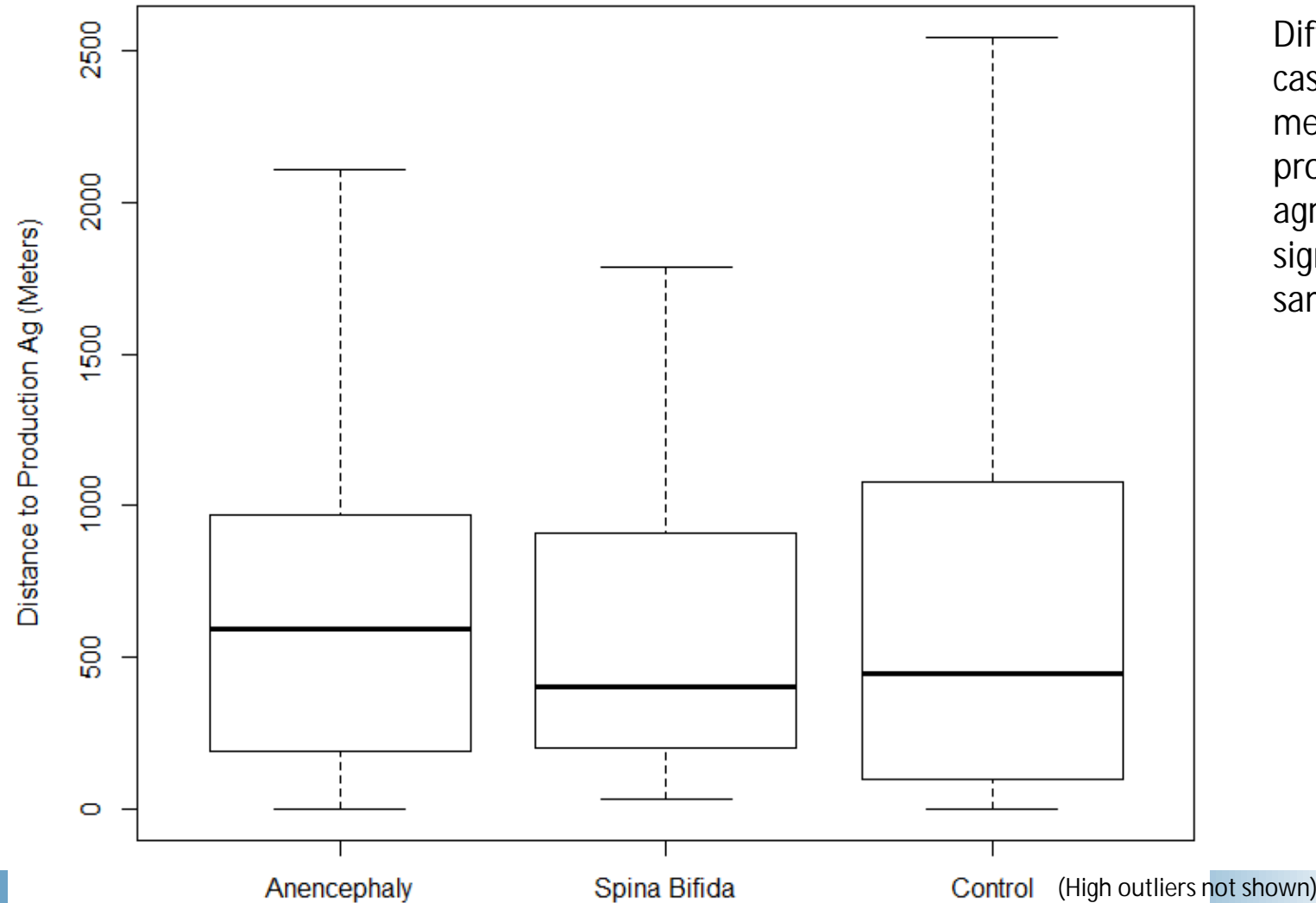
# Anencephaly Ascertainment Comparison

	All Cases		Hispanic Cases Only	
	3 County Area 2010-2016	NBDPS region 2004-2011	3 County Area 2010-2016	NBDPS region 2004-2011
	Washington	Texas	Washington	California
Live birth certificate	21%	37%	26%	39%
Fetal death certificate*	30%	41%	33%	29%
< 20 wks gestation	49%	22%	41%	32%

\*Operationalized as 20+ weeks at delivery and not live born

## Proximity to Production Agriculture (meters), 2010-2014

Case/Control	N	Minimum	1st Quartile	Median	Mean	3rd Quartile	Maximum
Anencephaly	34	0	190	592	737	971	2110
Spina Bifida or Encephalocele	18	32	203	405	548	850	1787
Control	42,200	0	100	446	672	1079	18870



Differences between case and control mean distances to production agriculture were not significant using 2 sample t- test

# Occupation

- Reported occupation of NTD cases based on birth or fetal death certificate reporting
- Certificates for 43 cases/37 had reported occupations\*

	Mother	Controls
Students	6%	2%
Clerks	8%	3%
Farm laborer	8%	3%
Housewife/househusband	28%	16%
Not Stated	33%	33%
	Father	Controls
Farm Laborer	3%	8%
Sports Instructor	5%	0.1%
Air conditioning/heating repair	5%	0.5%
Laborer	5%	4%
Construction laborer	5%	3%
Not Stated	38%	31%

\*Occupations include only reported occupations with more than one case mother or father

# Surveillance Summary

- Cases have occurred across all years with no strongly defined peak in time
- No seasonality in case occurrence
- Predominance of anencephaly among NTDs
- Rates from the three county area appear on the high end of state rates across the country
- More anencephaly ascertained earlier than TX & CA
- Cases and controls (live births/fetal deaths) same distance from production agriculture
- No occupations more frequent among case mothers or fathers



# Interview Update

# Interview Summary

	Mothers of Infants with any NTD	Mothers of infants with anencephaly
Total Number <sup>1</sup>	64	41
Number approached	34	22
Number Interviewed	17 (50% of Approached)	12(55% of Approached)
Mean Age at Conception	29 yrs	28 yrs
Hispanic Ethnicity	7 (41%)	6 (50%)
Mexico Born	4 (24%)	3 (25%)
More than HS	11 (65%)	7 (58%)
Prior pregnancy	16 (94%)	12 (100%)
Prior NTD pregnancy	3 (18%)	2 (17%)
Any Prenatal Vitamin (PNV)	17 (100%)	12 (100%)
PNV Use Critical Window	10 (59%)	8 (75%)
Mother worked	11 (65%)	9 (75%)
Occupational Pesticides	5 (29%)	4 (33%)
Exposed thr Farm Work	3 (18%)	3 (25%)
Any Pest. Use Home	6 (35%)	4 (33%)
Mother Applied Pest. Home	2 ( 12%)	1 (8%)
Occup & Home Pest. Exp	1 (6%)	1 (8%)

<sup>1</sup>Confirmed by October 10, 2015

# Interview Results - Summary

- Interviewed women slightly older than all birth mothers in area
- Interviewed women less likely to be Hispanic than all NTD cases
- Interviewed women were more likely to report prenatal and folic acid vitamin use than in PRAMS or the medical record case-control study, and they did not appear to be folate deficient
- Many interviewed women reported risk factors for NTDs
- About one third of interviewed mothers were assessed to have occupational exposures to pesticides, predominantly herbicides, not all through farm work.

# Case Control Analyses

- Plan to compare Washington interviewed cases to NBDPS controls from CA & TX from 2004-2011
- Will explore known risk factors for NTDs individually (family history, diabetes, Hispanic ethnicity, obesity, use of folate antagonists)
- Will explore parental occupational pesticide exposure using the NIOSH coded data
- Will determine whether additional analyses are indicated based on findings

# Prevention Update

# Intercept Interviews

Location	Health District	# of interviews
La Leche League meeting	Yakima	5
Yakima Valley Farmworker's WIC Clinic	Yakima	3
Yakima Public Parks	Yakima	7
Yakima Valley Community College	Yakima	2
Benton Franklin Health District	Benton-Franklin	16
Kennewick Farmer's Market	Benton-Franklin	5
Prosser Public Library	Benton-Franklin	4
<b>TOTAL</b>		<b>42</b>

<b>Interviewee demographics</b>	<b>Number</b>
<b>Age</b>	
25 years or younger.....	15
26-35 years.....	22
36-45 years.....	4
46 years or older.....	1
<b>Race and ethnicity</b>	
Asian, East Indian.....	1
Latina/Hispanic.....	16
Native American.....	1
White (non-Hispanic).....	22
<b>More than one race:</b>	
Native American and Black.....	1
Native American and White.....	1
<b>Insurance Status</b>	
Medicaid.....	21
Private insurance.....	17
None.....	4
<b>Pregnancy Status</b>	
Has children, not pregnant.....	26
Pregnant.....	9
Not pregnant, no children.....	7

# Getting Health Information

## Top preferences for receiving health information

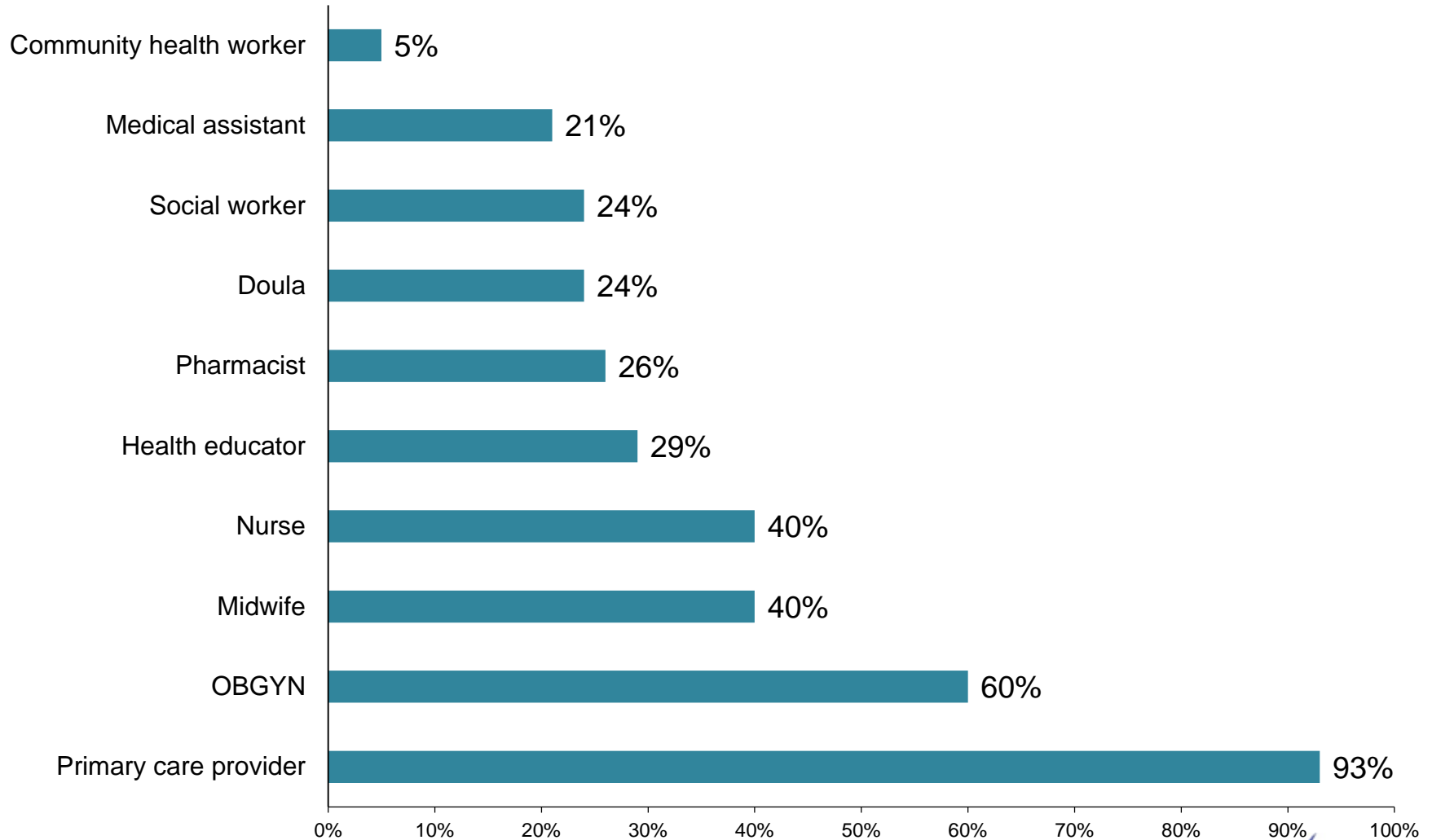
Latinas	Non-Latinas
<ol style="list-style-type: none"> <li>1. Health care providers or clinics</li> <li>2. Online</li> <li>3. Family and friends</li> </ol>	<ol style="list-style-type: none"> <li>1. Health care providers or clinics</li> <li>2. Family and friends</li> <li>3. Online</li> </ol>

## Top ways of hearing about current health issues

Latinas	Non-Latinas
<ol style="list-style-type: none"> <li>1. Articles on social media</li> <li>2. Local TV</li> <li>3. Online newspapers</li> <li>4. Grapevine/family/friends</li> </ol>	<ol style="list-style-type: none"> <li>1. Articles social media</li> <li>2. Grapevine/family/friends</li> <li>3. Local TV</li> <li>4. Online newspapers</li> </ol>



# Most Trusted Health Care Professionals



# Folic Acid Knowledge & Use

- About half of interviewees had not heard about folic acid prior to pregnancy
  - And they wished they had received more information
- 60% of interviewees started pre-natal vitamins or folic acid once they found out they were pregnant
- Almost 80% said they “definitely will ask their provider” for a prescription for pre-natal vitamins
  - Not a single interviewee with Apple Health (Medicaid) knew about the new coverage

# Folic Acid, cont.

- Top motivating factors for taking vitamins:
  1. Good for own health
  2. Good for baby's health
  3. Told to by doctor or midwife
- Top barriers:
  1. The vitamins make you sick
  2. Women don't know why they're important
  3. Women forget to take them

# Anencephaly Awareness & Concern

- About 70% of participants had never heard of anencephaly
- About half of participants wish they would have had more information about anencephaly prior to pregnancy
- Interviewees were more concerned about other birth defects (down syndrome, cleft palate) than anencephaly

# Recommended Outreach Strategies

1. Incorporate folic acid education into medical appointments
2. Use social media ads to raise awareness about folic acid
3. Share important health updates through local media

# Investigation Conclusions

- Elevated anencephaly rate likely due in part to more complete ascertainment of cases in three county area
- Case-control analyses and interviews of cases have not identified single preventable cause
- Despite pursuing multiple hypotheses, there is still no evidence that the elevated rate is due to folic acid deficiency, nitrates in drinking in water, pesticides or radiation from Hanford
- No identified prevention opportunity beyond promotion of preconception folic acid use
- Resources should be focused on outreach to educate women about prevention and early detection of neural tube defects, and promotion of preconception and pregnancy health

# Recommendations for Future Activities

- Complete comparison of case-control data and end investigative component of response if no hypothesis identified. Incorporate investigation findings into report. Review draft report with Advisory Committee in Fall 2016 and finalize
- Continue surveillance through August 2017 and review findings at that time. Determine continued surveillance efforts in Fall 2017
- Incorporate lessons learned from intercept interviews into continued outreach, development of preconception and pregnancy materials, and efforts to improve access
- Continue work with local health and other partners on folic acid outreach, communication and improvement of preconception and pregnancy health

# Questions/Comments?



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)