



PUBLIC HEALTH
ALWAYS WORKING FOR A SAFER AND
HEALTHIER WASHINGTON

Anencephaly Investigation
Central Washington, 2010-2014

Advisory Committee Meeting
July 28, 2014

WHAT WE'VE LEARNED SINCE ADVISORY COMMITTEE MEETING ON JUNE 16, 2014

Surveillance Questions

- Do we know that we have identified all cases in this 3-county area?
- How do rates in the 3-county area compare to other rural agricultural communities?
- Do we know if this cluster is new or has been going on for a while?
- Do we know that rates of anencephaly in this area are different from the rest of the state?
- What are ongoing options for surveillance?

Surveillance Questions

- Do we know that we have identified all cases in this 3-county area?
 - Can never be sure we have all cases, but have ascertained as well as any active birth defects registry
 - May have missed cases of mothers who moved out of the area during pregnancy
 - May have missed cases diagnosed very early in pregnancy and terminated at clinic or facility outside 3-cluster area

Surveillance Questions

- How do rates in the 3-county area compare to other rural agricultural communities?

Neural Tube Defect and Anencephaly Rates* among Hispanic and Non-Hispanic Whites in rural agricultural areas

		All Neural Tube Defects		Anencephaly	
		Hispanic	NH White	Hispanic	NH White
3-County Area, Washington	2010-2013	10.3 (6.1, 16.3)	10.3 (5.6, 17.3)	8.6 (4.8, 14.2)	7.4 (3.5, 13.6)
Central Valley California	1997-2006	7.7 (6.8, 8.6)	7.9 (6.6, 9.2)	na	na
California registry (30% of state)	2006-2010	na	na	2.9 (2.2, 3.7)	1.5 (0.8, 2.5)
Rural Texas - thinly populated	2006-2009	na	na	2.9 (1.5, 4.9)	1.7 (0.8, 3.1)
Rural Texas - 36% or more in crops	2006-2009	na	na	2.7 (2.0, 3.6)	1.9 (1.1, 3.0)

*Rates per 10,000 live births and 95% confidence Intervals

Surveillance Questions

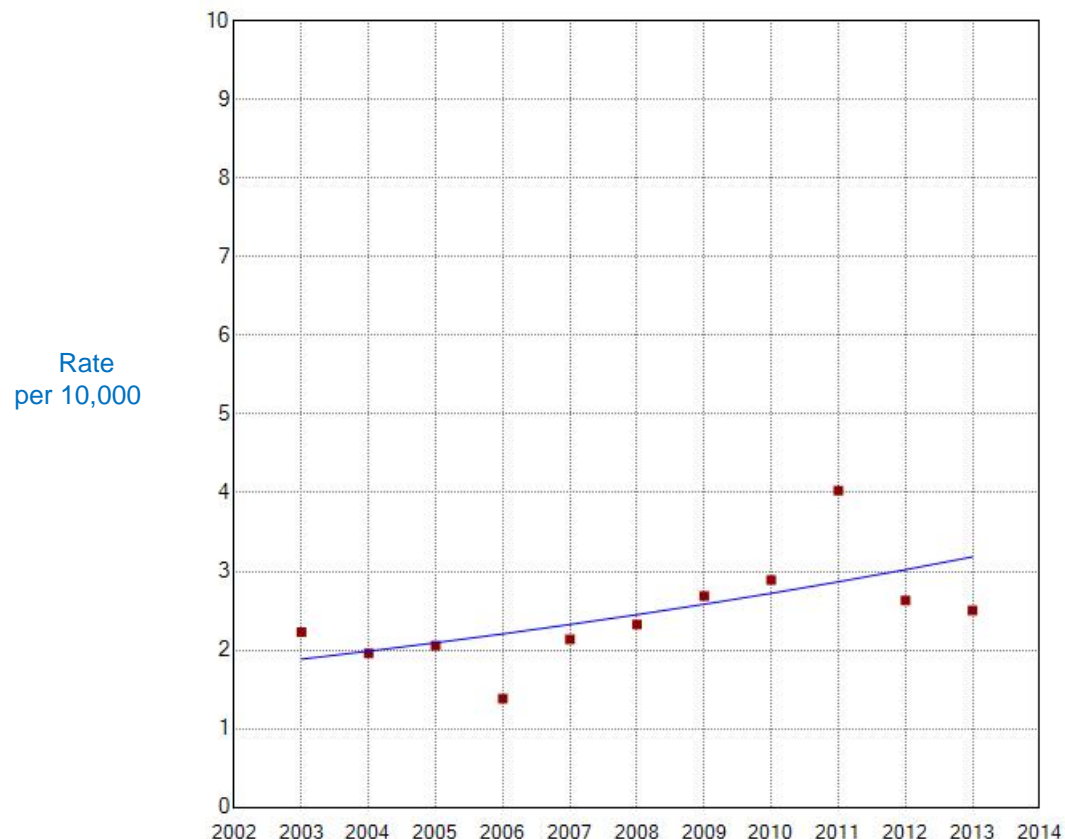
- Do we know if this cluster is new or is an increased rate that has been going on for a while?
- Do we know that rates of anencephaly in this area are different from the rest of the state?

Washington Rates of Anencephaly & Spina Bifida*

	Anencephaly	Rate per 10,000	Anencephaly & Spina Bifida	Rate per 10,000	Births
2003	18	2.2	35	4.3	80,482
2004	16	2.0	29	3.5	81,715
2005	17	2.1	30	3.6	82,625
2006	12	1.4	29	3.3	86,845
2007	19	2.1	39	4.4	88,921
2008	21	2.3	44	4.9	90,270
2009	24	2.7	35	3.9	89,242
2010	25	2.9	34	3.9	86,480
2011	35	4.0	49	5.6	86,929
2012	23	2.6	42	4.8	87,417
2013	22	2.5	42	4.9	86,566
2003-2013	232	2.4	408	4.3	947,492

* Based on ascertainment from birth and fetal death certificates

Trend in Anencephaly ascertained from Vital Statistics, Washington 2003-2013



Note that this trend only includes live births and fetal deaths, and does not take into account population changes which may be impacting the rate, or differences in termination over time.

Additional analyses

- SatScan spatio-temporal clustering
- Identified “clusters” covering large areas of Eastern Washington
- Don’t know whether these “clusters” are just reflecting population differences. The area has a higher proportion of Hispanics who we know have higher rates of anencephaly. The “cluster” could also be reflecting differences in pregnancy termination after a diagnosis of anencephaly.
- Even with statewide data, very low power to detect a small area cluster.

Surveillance Questions

- Do we know if this cluster is new or is an increased rate that has been going on for a while?
- Do we know that rates of anencephaly in this area are different from the rest of the state?

Surveillance Questions

- What are ongoing options for surveillance?

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

Additional Investigation of Cause

- Desire to know as much as we can
- No strong and specific hypotheses
- What is feasible
- Discussions with CDC and birth defects experts
- Presented at annual Teratology Society meeting
- Piggy-back existing study to learn more

National Birth Defects Prevention Study

- Explores environment, behavioral and genetic factors related to several birth defects, including anencephaly
- 10 states
- 1997-2011
- Mothers of 2,231 babies with neural tube defects participated
- 60-minute phone interview

National Birth Defects Prevention Study

- Maternal health
- Pregnancy history
- Nutrition and diet
- Substance use
- Demographics
- Water use
- Occupation
- Residence

Prevention

- Many partners are interested in collaborating on prevention
- Focus on public education, provider education and developing folic acid resources
- Several activities are already underway or planned
- Public education
 - Public Service Announcements
 - Distribution of brochures

Prevention

- Public education continued
 - Newspaper ads
 - Spanish language radio programming on health issues
- Provider education
 - Local health communication to providers
 - Presentations to providers

Prevention

- Nitrates in drinking water
 - GWMA is collecting names of people for free well water inspection and testing. Had a contract with a company that expired but they want to continue to offer this.
 - Provider education planned by UW Pediatric Environmental Health Specialty Unit faculty
- FDA reviewing Folic Acid fortification of corn masa flour

Questions?

ACTION PLAN

Primary Goals

- Identify ways to improve reporting of neural tube defects to better ascertain rates of occurrence
- Determine if additional investigation should be conducted to assess potential exposures, and what specifically is recommended as next steps
- Identify actions to prevent or reduce the likelihood of neural tube defects in the area

Draft Action Plan

- Surveillance
- Investigation of cause
- Prevention

Working Plan for Surveillance

Activity	Outcome	Timeline	Staffing Resources
<p>Statewide passive surveillance using vital statistics and the linked Birth-Hospitalization file</p>	<p>Ongoing monitoring of NTDs identified at birth to determine statewide and regional trends</p>	<p>Quarterly reporting through July 2015 – 6 month lag time</p>	<p>DOH staff epidemiologist</p>
<p>3-county area – ongoing stimulated passive surveillance from hospitals and providers w/active follow-up</p>	<p>Ongoing monitoring of NTDs across 3-county area</p>	<p>Quarterly reporting through July 2015</p>	<p>DOH staff epidemiologist</p>

Working Plan for Additional Investigation of Cause

Activity	Outcome	Timeline	Staffing Resources
<p>Interviews with mothers of infants with anencephaly who were residents of 3-county area and had an estimated date of delivery within 2 years of interview (from 8/2012 to present)</p>	<p>Identification of frequent exposures among case mothers. Can compare to information from National Birth Defect Prevention Study and population data.</p>	<p>Preliminary: August 2014 – March 2015 establish and complete data collection and data sharing; April 2015-June 2015 data analysis; July 2015 data presentation</p>	<p>Working with CDC to identify resources for interviews. Details still need to be worked out.</p>

Working Plan for Prevention – Public Outreach

Activity	Outcome	Timeline	Staffing Resources
<p>Public Service Radio spots. March of Dimes has contacted radio stations in Eastern WA and provided links to PSAs promoting folic acid use.</p>	<p>Women of child-bearing age in Benton, Franklin and Yakima counties informed about the importance of folic acid use.</p>	<p>June 2014 – ongoing</p>	<p>March of Dimes</p>
<p>Folic acid brochures & materials in Eng. and Sp. sent to hair and nail salons, community and technical colleges</p>	<p>Women of child-bearing age in Benton, Franklin and Yakima counties informed about the importance of folic acid use.</p>	<p>July 2014</p>	<p>March of Dimes</p>

Working Plan for Prevention – Public Outreach

Activity	Outcome	Timeline	Staffing Resources
<p>Folic acid brochures & materials in Eng. and Sp. to health care and social service providers for dissemination</p>	<p>Women of child-bearing age in Benton, Franklin and Yakima counties informed about the importance of folic acid use.</p>	<p>August 2014 – July 2015</p>	<p>DOH and local health staff</p>
<p>March of Dimes will contact newspapers in Central WA and provide folic acid banners and messages to include in the paper</p>	<p>Women of child-bearing age in Benton, Franklin and Yakima counties informed about the importance of folic acid use.</p>	<p>August 2014 - ongoing</p>	<p>March of Dimes</p>

Working Plan for Prevention – Public Outreach

Activity	Outcome	Timeline	Staffing Resources
Hispanic Health Commission/Dept. of Health radio programming collaboration	30 minute radio show in Spanish on investigation and prevention opportunities - syndicated to several stations	August or September 2014	State Epidemiologist State Health Officer DOH staff
Anencephaly Investigation web page on DOH website	Continue to promote folic acid use by women of reproductive age	Ongoing	State Epidemiologist DOH staff
Women's Health webpage and fact sheets w/folic acid message	Continue to promote folic acid use by women of reproductive age	Ongoing	DOH Prevention and Community Health

Working Plan for Prevention – Provider Outreach

Activity	Outcome	Timeline	Staffing Resources
Local health communication to providers: blast fax, articles in medical society newsletters	Inform all health care providers in 3-county area about the increased rate, investigation, case-reporting and prevention	August 2014	State and Local Health Officers Central and Eastern WA Perinatal Regional Network partners
Presentations: OB Grand Rounds 8/27/14 Yakima; TBD Benton-Franklin	Inform all health care providers in 3-county area about the increased rate, investigation, case-reporting and prevention	August – December 2014	State Epidemiologist State Health Officer Local Health Officers Perinatal Partners

Working Plan for Prevention – Provider Outreach

Activity	Outcome	Timeline	Staffing Resources
<p>Development and dissemination of materials for providers on</p> <ol style="list-style-type: none"> 1) Discussing pregnancy planning 2) Promoting folic acid use to women of reproductive age 	<p>Health and social service providers have resources to assist them with conversation regarding pregnancy planning and folic acid use</p>		

Working Plan for Prevention – General

Activity	Outcome	Timeline	Staffing Resources
<p>Convene monthly phone call of state and local public health, March of Dimes, Perinatal Regional Network coordinators and others to coordinate ongoing prevention efforts</p>	<p>Coordinated ongoing prevention efforts which take advantage of existing meetings, trainings, public forums, and other opportunities</p>	<p>August 2014 – July 2015</p>	<p>State and local public health staff, March of Dimes, Perinatal Regional Network coordinators and others</p>

Working Plan for Prevention – Folic Acid

Activity	Outcome	Timeline	Staffing Resources
Subsidize Folic Acid Vitamins	Increased access to folic acid containing vitamins for low income women of reproductive age		Explore whether Memorial Fdn., Yakima Valley Community Fdn, Legends Casino or others willing to support
Folic Acid fortification of corn masa flour – Letter of support to FDA	Washington State support for FDA approval of folic acid fortification of corn masa flour		

To provide comments or questions,
please contact:

Cathy Wasserman, PhD

State Epidemiologist for Non-Infectious Conditions

Washington State Dept. of Health

PO Box 47890

Olympia, WA 98504-7890

cathy.wasserman@doh.wa.gov

PUBLIC HEALTH

ALWAYS WORKING FOR A SAFER AND

HEALTHIER WASHINGTON