

**Anencephaly Advisory Committee Meeting (webinar)**  
**Minutes**  
**June 11, 2015**

**Advisory Committee Members present:**

Kathy Lofy, MD, Chair  
Sara Barron, RN  
Amy Person, MD  
Melissa Schiff., MD, MPH  
Sarah Tinker, PhD  
Vickie Ybarra, PhD, MPH, BSN

**WA Dept of Health Staff present:**

Mandy Stahre, PhD, MPH  
Cathy Wasserman, PhD, MPH

Interested parties were sent information about the meeting and asked if they wanted to participate. There were several interested parties on the call, including representatives from the media.

**I. Welcome and Introductions**

Cathy Wasserman began the meeting at 8:00 am with a quick introduction and proceeded to provide an update on prevention activities.

**Prevention Efforts Update:**

- Efforts continue to focus on folic acid supplementation for all women of childbearing age
- DOH is developing tools for providers and community health workers with general information about folic acid as well as how to access free materials for women. These materials will be disseminated to community health workers at upcoming conference in Granger.
- DOH has contracted for the March of Dimes 30 second radio messages which are airing in English and Spanish throughout the 3-county area.
- DOH has also contracted to air a 12 episode radio novella that focuses on preconception messages, including folic acid. The radio novella is airing in Spanish.
- Yakima Health District continues to communicate with Vitamin Angels to secure and distribute subsidized vitamins
- DOH continues to monitor the March of Dimes efforts regarding supplementation of corn masa flour with folic acid.

**Addressing previous questions from April 28 meeting.**

- Have one more year of PRAMS (Pregnancy Risk Assessment Monitoring System) data on vitamin use. Rates for 2010-2012 continue to show lower rates of vitamin use in the 3 county area. A higher percentage of women in the three county area reported never using folic acid in the month before pregnancy compared to the rest of the state.
- Data from the Washington State Birth Defects Registry from 1987-1988, when it was an active registry:
  - 9 infants in the three county area with neural tube defects. The rate was 8 per 10,000 livebirths and none of the cases were anencephaly. Caveat – there have been population demographic shifts since the 1980s. In addition, these data predate folic acid supplementation which began in 1998.
  - Confidence intervals show rates are not statistically different from current rates.

- Explored whether WA has more complete case ascertainment in the three-county area compared with other surveillance areas.
  - All cases from 2010-2015 – 61 NTD affected pregnancies identified
  - 19 of the 61 ended before 20 weeks gestation, including 18 anencephaly
  - Rate of Anencephaly among all pregnancies – 9.0 per 10,000
  - When only include anencephaly  $\geq$  20 weeks: 5.4 per 10,000
  - Additional rates calculated if only include 17+ weeks or 15+ weeks gestation
  - Conclusion: Including all cases regardless of gestational age of pregnancy does impact our rates, but it appears that our increased rates are not solely due to better ascertainment.
- Explored abortion rates by gestational age in WA and the three counties. The percent of all abortions that were second trimester was similar across the three counties and WA state. This analysis is not very informative for our investigation.

Questions:

Advisory Committee (AC): Are differential abortion rates across areas contributing to differences in NTD rates? Can you calculate an anencephaly rate across all (total) pregnancies?

DOH: We can look to see what the number is. The standard rate for birth defects uses live births (compared to all pregnancies) as the denominator.

Advisory Committee (AC): Anencephaly pregnancies were identified prior to 20 weeks' gestation. How were these identified?

DOH: Some were identified through terminations or spontaneous abortions. If the denominator is all pregnancies, then the numerator would have to be for all NTD-affected pregnancies. May look at live born and fetal deaths in the numerator for the three county area and compare it to the rest of the state.

CDC: There are groups where NTD rates are higher and there are also groups where abortions are more likely to occur. CDC would be happy to help tease out some of these analyses.

Advisory Committee (AC): Is there any place else in the country experiencing a spike:

CDC: Not that we are aware of except the border of Texas and Mexico.

Advisory Committee (AC): Is there a relationship of how close women live near agricultural fields or is dose-related by distance to fields?

DOH: We did an initial look with the original case-control study and didn't find a difference. We are looking into repeating the analysis with current cases.

Advisory Committee (AC): I saw some studies that showed that 1000 mcg of folic acid was effective and anything less was not effective.

CDC: We're finding that most women benefit from 400 mcg and some women are asked to take more especially if they have already had an NTD-affected pregnancy.

General Public(GP): How are the interviews with the mothers being conducted? By phone or in person interview and if by phone is that a barrier? If some women are declining they may be more likely to participate in-person rather than phone.

DOH: They are being conducted by phone. We have had several outright declines. Some women we were never able to identify a time that worked for them or our times were set up and they

weren't available. Several women we were not able to reach through several phone numbers and call attempts. We have undertaken many efforts to contact women.

General Public: If fetal deaths are only reported after 20 weeks, how are you getting the earlier cases?

DOH: We have actively contacted hospitals and asked them to go through their medical records to look for NTD diagnoses. We have asked providers to report NTD affected pregnancies and we have contacted nurse/OB managers to report cases.

Next meeting:

- August 13 (8:00 am, Thursday) next data update.

Call ended at 9:00