

**Anencephaly Advisory Committee Meeting (webinar)
Minutes
September 18, 2014**

Advisory Committee Members present:

Kathy Lofy, MD, Chair
Susie Ball, MS LCGC
Philip Halvorsen, MD
Lisa Galbraith, MD
Amy Person, MD
Kathleen Rogers
Melissa Schiff, MD, MPH
Christopher Spitters, MD, MPH

WA Dept of Health Staff present:

Lillian Bensley, PhD
Mandy Stahre, PhD, MPH
Cathy Wasserman, PhD

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

Kathy Lofy began the meeting a few minutes past 8:00 am with introductions. There were no comments on the draft minutes from the July 28th meeting.

Minutes approved from July 28th.

Cathy Wasserman gave presentation (attached) Some main points of slides are listed below.

Surveillance Updates:

- Dept of Health will continue to monitor NTDs in the three county area with passive surveillance, and statewide using vital statistics files.
- Dept of Health will update the prevalence tables with cases confirmed through Sept 30, 2014 at the next meeting on October 20th.

Investigation Updates:

- Conducted a re-analysis of the case control data limited to the anencephaly cases.
- Observed one change related to folic acid use. Women who did not take folic acid in early pregnancy had a decreased odds ratio for anencephaly.
- This finding is similar to original report but is statistically significant in analysis limited to mothers of anencephalic infants.
- We believe the reason for this finding is that providers collected more information on vitamin use from mothers of infants with an NTD. Women were classified as not using if there was no information in the chart. We will follow up in the interview study to get better ascertainment.
- Folic acid is still considered the primary prevention strategy for NTD.
- Continue to prepare for the interview study and will use the National Birth Defects Prevention Study questionnaire.
- Plan to approach mothers of all infants with anencephaly and spina bifida with a due date within 2 years of the study start (October 15, 2014)
- Access to comparison data is still being investigated.

- Hypotheses to further explore with the interview data include:
 - Folic acid supplementation and food folate
 - Public vs. private water source
 - Nitrates in drinking water and nitrosatable drug exposures
 - Parental agricultural occupations

Prevention Activities Update

- Begun to hold monthly prevention calls with state and local health staff, perinatal coordinators and non-profit representatives to coordinate prevention measures. The next call is Monday, Sept 22 at 9:00 am.
- Provider outreach
 - Yakima and Benton/Franklin Health districts have sent a blast fax to providers about the investigation, folic acid supplementation as a prevention strategy, and asking them to report NTD diagnoses directly to the Dept of Health.
 - Alert was also sent to all local health officers across the state]
 - Grand Rounds have been presented at Kadlec Hospital, Yakima Memorial Hospital and one is planned for the University of Washington.
- Public outreach
 - DOH anencephaly webpage updated
 - Planned radio show focused on the anencephaly investigation in collaboration with the Hispanic Commission in November.
 - Presented anencephaly investigation to Yakima Board of Health
 - Identified new opportunities for messaging and distribution of materials.
 - Yakima county fair will have a table with folic acid and women's health materials

End of presentation

Questions from Advisory Committee members:

AC: Should we continue to use the forms to report cases with Mandy's name on them?

DOH: The contact person should be Lillian Bensley. Her number is 360-236-4248 We will update the forms.

AC: One of the screens showed 23 of 42 cases, I'm not sure what it was you were showing us. Which counties were those in?

DOH: We are planning to interview women with a due date up to two years before the interview. Our investigation started in January 2010. We are not going to interview women in that early period because that is different from the protocol from the National Birth Defects Prevention Study. Many of these women have had subsequent pregnancies and want to hone in on time period they can effectively remember. The number of cases drops to about 23 women with a due date of Oct 2012 and subsequently. We haven't looked at what counties, but imagine they will be from Benton/Franklin and Yakima counties.

Kathy Lofy: Some of this work has been included into a subgroup, the Prevention Workgroup. If Advisory Committee members are interested in participating on these calls, we can send the information. Please contact Cathy Wasserman.

Questions from the general public:

GP: There have been hypotheses regarding fungus producing toxins in masa in other studies. Have you considered ways to examine this?

DOH: We have considered this. It is our understanding that the fungus is in masa and other grains as well. The distribution of fungus would have been disseminated beyond the investigation area. It is unclear if it is a viable hypothesis.

Kathy Lofy: The investigator had collected corn products from the Yakima area and remarked that the products had been produced around the country. It does seem like if products had been produced all over the country, why would we just see an increase in this particular area? We could look at the distribution patterns of these products.

AC: Don't think it's a bad idea. Have found ugly mold on corn that I'm growing. I have a question. It seems like in our cities, they add fluoride to our water. I'd like to know what the differences are. Is there another way we could have women take folic acid in other ways? Is there a way to add the folic acid the way they add the fluoride?

DOH: I am not as familiar with the original studies on folic acid fortification in grains and how the decision to fortify grains was decided.

GP: Have you got any initial results you can share from the 3rd quarter to date in terms of the surveillance? And is there anything you can share regarding the initial surveillance from other parts of the state?

DOH: We do not have initial results to share, we will be able to share them at the October meeting. The initial state results were reported at the previous meeting and are available on the [DOH website](#).

Next meeting will be October 20th.

Adjourned 8:30am