

**Anencephaly Advisory Committee Meeting (webinar)
Minutes
October 20, 2014**

Advisory Committee Members present:

Kathy Lofy, MD, Chair
Richard Olney, MD, MPH
Peter Langlois, PhD
Philip Halvorsen, MD
Jennie McLaurin, MD, MPH
Lisa Galbraith, DO, MPH
Amy Person, MD
Christopher Spitters, MD
Vickie Ybarra, PhD, MPH, BSN
Gina Legaz, MPH

WA Dept of Health Staff present:

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

Meeting started at 8:04 am. There were technical difficulties with the GoToMeeting site. Specifically, in Olympia, we could not hear advisory committee members at first, and they had to call in several times. We also received feedback after the meeting that members could not hear us the entire meeting.

Kathy Lofy began the meeting at 8:04 am with a quick introduction.

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

Surveillance Updates:

Following a stimulated passive approach.

- Sent a health alert to providers in the 3 county area and to health officers across the state. Emphasized prevention messages and that providers in the 3-county area or treating patients in the 3 county area should contact Dept. of Health directly with identified cases.
- Followed up with hospitals in area to identify new cases
- Reviewed preliminary 2014 vital statistics data through September.
- Looked at file which links birth and fetal death data to hospital discharge data for 2010-2012 which is the most recently available file.
- All possible cases were followed up to confirm their status.

8 additional cases were identified through the continued surveillance.

- 50 cases of NTD identified with estimated date of delivery since January 2010 including 37 cases of anencephaly.
- 2 cases identified from earlier years.

- Estimated date of delivery extended to 2015.
- No seasonality in cases observed.
- Updated rates for 2010-2013 by county were presented.
- Next update of case numbers will be in mid-January 2015.

Investigation Updates:

- 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 within a few weeks.
- Continue to work to gain access to comparison data from NBDPS.

Prevention Activities Update

- Continuing monthly prevention calls with state and local health staff, perinatal coordinators and non-profit representatives to coordinate prevention measures.
- Provider outreach through grand rounds and trainings
- Making sure materials are available at annual meetings/trainings throughout the state
- Update anencephaly website on DOH
- Promote folic acid use
- Spanish language radio show scheduled for early November in collaboration with the Hispanic Commission
- March of Dimes has contacted news and print media in 3-county area to tell them about free banner ads available
- Challenge remains convincing women to take folic acid to prevent NTDs.

End of presentation

Questions from Advisory Committee members (some technical difficulties in hearing DOH):

Advisory Committee (AC): Any update on corn masa fortification?

DOH: No update on FDA approval on fortifying folic acid.

AC: There has been an additional letter about the inclusion of folic acid on nutritional labels and DOH signed on to it. A lot of radio stations are picking up the folic acid public service announcements – in both English and Spanish.

Questions from General Public (GP)

GP: Any questions about the consumption of corn or corn-based foods?

DOH: I'm not sure exactly what you are asking. If you are asking about the questionnaire, it includes a food frequency questionnaire that does ask about corn tortilla consumption.

We will schedule two additional check in meetings in two and four months' time.

Adjourned 8:28 am