

**Anencephaly Advisory Committee Meeting (webinar)
Minutes
March 12, 2015**

Advisory Committee Members present:

Kathy Lofy, MD, Chair
Susie Ball, MS LCGC
Nora Coronado, PhD, MPH, MSW
Lisa Galbraith, DO, MPH
Peter Langlois, PhD
Jennie McLaurin, MD, MPH
Richard Olney, MD, MPH
Amy Person, MD
Melissa Schiff., MD, MPH
Christopher Spitters, MD
Vickie Ybarra, PhC, MPH, BSN

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 a quick introduction and turned the meeting over to Cathy Wasserman.

Cathy Wasserman asked the group if they would approve the minutes to the meetings held 10/20/2014 and 1/15/2015 so that they could be published to the DOH website. The group approved the minutes which were posted to the website by the end of the day on 3/12/2015.

Cathy Wasserman gave a very brief presentation updating advisory committee members on the status of surveillance, investigation and prevention efforts. (attached) Cathy noted that DOH has completed 11 interviews from among the 25 women eligible. One or two moms are scheduled for interview. Two mothers have declined to participate. DOH continues to have problems contacting the remainder of the women, and has reached out to providers for updated contact information. DOH has followed the NBDPS guidelines on contacting mothers.

The remainder of the time was spent on questions and comments from the Advisory Committee members and the public.

Questions from Advisory Committee members are interspersed with the presentation:

Advisory Committee (AC): How will providers know to report?

DOH: We have sent notices to providers via newsletters from the local health jurisdictions asking providers to report directly to DOH. Some providers have contacted us directly. We are actively contacting hospitals in the three county area, periodically, and asking them to do an extract from their discharge diagnoses to identify potential cases. We follow up and ask for medical records for potential cases, and have also touched base with obstetric nurses to

identify potential cases. Our next update of case numbers will be in April with the new cases identified to date.

(Note: Chris Spitters, Health Officer from Yakima Health Jurisdiction, offered to send another reminder to providers.)

Advisory Committee (AC): How long does the interview take?

DOH: A little over an hour to hour and a half. We do allow women to complete the interview in multiple sittings.

AC: Have you had any interviews that were given in Spanish only?

DOH: Yes, we've had some that were Spanish only. We have sent recruitment letters in both English and Spanish. If our English interviewer contacts a woman who is Spanish speaking, then our Spanish-speaking interviewer will contact them.

AC: Are you interviewing just mothers of anencephalic infants or all NTDs?

DOH: We are interviewing mothers of all infants with an NTD.

AC: I have a patient who had a NTD but has not been called to interview.

DOH: Please follow up with us and we will check to see if the woman is eligible for interview. We are following the NBDPS protocol and women whose estimated due date was within two years of right now are eligible for interview.

DOH: We are still following up to get data from the National Birth Defects Prevention Study to use to compare to mothers in the three county area.

DOH: We initially presented data last June on cases from our medical records study, and found that about 77% of case mothers had public water supplies. We have been able to extract information for mothers of cases identified since and 80% of all case mothers identified through January 9, 2015 were on public water supplies.

AC: Are there any differences by county? People who live near Hanford are concerned of nuclear waste in the water supply.

DOH: We have not looked at it by county, but we can look. We may not be able to determine who is drawing water from the Columbia River. These public water supplies are monitored. Usually if there has been a leak it has been on the Hanford Site itself.

DOH: With respect to Prevention Activities:

- Provider outreach continues with presentations at conferences.
- We are working with a public relations firm to disseminate preconception focused radio novelas in Spanish.
- We understand there is possible movement of folic acid fortification of corn masa flour at the federal level
- There is a study collecting questionnaires and biological samples that includes women delivering in Yakima. There may be a way to look at blood levels of folate and vitamin use of a convenience sample of women in Washington State. We need to follow up with the study coordinators.

AC: Have you spoken with anyone from FDA or March of Dimes about the fortification of corn masa flour?

DOH: No, we asked a retired CDC employee who has been very active in the folate fortification efforts. He advised us to wait before contacting FDA because it appears that stability studies are underway.

AC: Have you heard about the group called Vitamin Angels? They are a nonprofit that have lots of funding and give free generic form vitamins for prenatal and children. They could supply the three counties with vitamins if it's an issue. I can give you their contact information.

AC: I heard that Gina Legaz from March of Dimes has approached the Health Care Authority to approve payments for prenatal vitamins and folic acid for women on Medicaid. Chris Spitters helped generate cost estimate for Yakima County and estimated it for Medicaid population. The cost was about \$250,000 per year.

AC: Where are you with community outreach other than radio? There appears to be a number of people who are poised and ready to help the women. Are you all developing that or is in the works.

DOH: Can you elaborate by what you mean that people are poised and ready? We have been working with March of Dimes on getting messages out.

AC: I just attended a conference with community health workers (CHWs) At this meeting, there were CHW's from all three counties who said they have not seen anything regarding materials around this topic. They are eager to get some materials and participate in prevention efforts.

DOH: we do have pamphlets and fliers and posters to disseminate materials from CDC and March of Dimes to the CHW's and we can inform them where to get more materials. In terms of the radio spots, the March of Dimes had contacted radio stations about the free radio spots and television about the banner ads. It's voluntary whether the stations run them or not. We are buying radio time in the area to air the preconception messages which include the folic acid message. Unfortunately, we don't have the budget to continuously pay for radio spots.

AC: Are you sending the pamphlets to public schools and sending them home with the kids? Or preschools or Headstart? Where are the educational materials going?

DOH: We have sent materials to health departments, March of Dimes has sent materials to community colleges, technical colleges, hair salons, and we have had them at county fairs last fall. March of Dimes has given a small grant to Yakima to help with dissemination of materials. We know WIC offices do distribute information on folic acid with their materials.

AC: What agency received money from MOD?

DOH: Karly Floyd, the perinatal regional coordinator in Yakima.

AC: It would be good to know where materials are being sent.

Open for additional questions from the advisory committee members
No more advisory committee questions.

Open for additional questions from members of the public:

Public: A member of the public contacted a radio station and that station did not know about the Spanish radio program which aired in Seattle.

DOH: We did check with radio KDNA in the three county area, and did ask them to air the show. We will follow up with them and get back to you.

Email question: Why are we not asking moms for folic acid or folate levels in light of the fact these women would be at risk for another anecephalic birth?

DOH: Part of our message to providers is that these women should be taking folic acid levels higher than that recommended for women of childbearing age.

Public: Will you be able to assess levels of nitrate from water?

DOH: We are doing interviews with case mothers currently. Control data will come from the National Birth Defects Prevention Study. We will try to look at the nitrate levels in the case moms and if there is indication that it is elevated, then we will try to do a sample of women in the three county area. The study has information on nitrosatable drugs, foods, and some questions on water, but may not get at nitrate levels in drinking water.

Public: Are you able to include women who choose to terminate pregnancies or only hearing from providers of women who take to term?

DOH: We are including all pregnancies affected with neural tube defects regardless of length of gestation. We are looking at stillbirths, late terminations, as well as live births.

Public: Can you reveal the zip codes of the women who have had NTD?

DOH: No, we are not revealing the zip codes to protect the confidentiality of the women.

Public: Is there any support Environmental Protection Agency can provide?

DOH: We will probably follow up offline as we cannot think of anything right now.

No more comments or questions.

Discussion of upcoming meetings:

- April 28th (8:00am, Tuesday) will be next meeting and updated numbers will be presented.
- Discussion of whether to hold meetings in June and August.
- Will hold meeting on June 11th to focus on public outreach
- Will hold meeting on August 6th or 13th with new data