

Local Health Department Reporting of Zika in Pregnancy and the US Zika Pregnancy Registry

December 2016

CDC has established a national, voluntary Zika Pregnancy Registry to address the many questions that remain about Zika-associated birth defects and other pregnancy outcomes. The US Zika Pregnancy Registry is being used for national estimates and to monitor symptomatic and asymptomatic pregnant women with laboratory evidence of possible Zika virus infection and their pregnancy outcomes.

Starting in late May, 2016, CDC began weekly reporting of the total number of pregnant women who are being actively monitored in the US Zika Pregnancy Registry as well as the number of liveborn infants and pregnancy losses with birth defects associated with Zika infection.

What does the Registry include?: The US Zika Pregnancy Registry data collection points include: the time of maternal diagnosis, 2nd trimester, 3rd trimester, delivery, and infant follow-up at 2, 6, and 12 months.

What is CDPH doing?: CDPH is participating in the US Zika Pregnancy Registry and CDPH is the point of contact for Registry data submission to CDC. CDPH will work with local health departments and health care providers to complete the US Zika Pregnancy Registry data collection forms and submit data to CDC. The Zika Pregnancy Registry activities at CDPH are being led by the California Birth Defects Monitoring Program (CBDMP) and conducted in coordination with efforts to achieve enhanced surveillance of Zika-related birth defects in California.

Zika virus infection is a reportable communicable disease in California (Title 17, California Code of Regulations). When CDPH receives a Zika case report for a pregnant woman or infant, the CDPH Zika Pregnancy Registry Coordinators review the report and Maternal Health History and make contact with the Local Health Department (LHD) to provide information and assistance with data collection based on LHD preferences. Following delivery, CBDMP abstractors review hospital medical records in order to collect Neonatal Assessment data and additional maternal health history if available. Efforts are deployed to ensure contact with the family in order to conduct infant follow-up and to provide support and referral to services as needed. CDPH Zika Pregnancy Registry Coordinators monitor receipt of Infant Follow-up forms and make contact with the LHD or provider to gather outstanding data as needed.

LHD responsibilities:

- 1) **Test Requests** – When contacted by a health care provider requesting initial Zika testing or confirmatory testing, assess the following and note for your own records:
 - Travel or other exposure history
 - Pregnancy status basics (When is she due? Any concerns for Zika related complications?)
 - Provider's contact information
 - Mother's contact information

2) **Case Investigation and Reporting** – For all pregnant women, with or without symptoms, who have any laboratory evidence of possible Zika virus infection. **Timeline:** Within 72 hours.

- Communicable Disease Reporting - Complete the **CDPH Zika Case Report**. This should be completed within 72 hours via CalREDIE or, if not using CalREDIE, submitted directly to the CDPH Division of Communicable Disease Control (DCDC) via fax to 916-552-9725 or via secure email to charsey.porse@cdph.ca.gov.

The CDPH Zika Case Report form can be found here:

<http://www.cdph.ca.gov/pubsforms/forms/CtrldForms/cdph8680.pdf>

(Note: Include sexual contact history under “Other Suspected Exposures”.)

- California Zika Pregnancy Registry - Complete the CDC **Maternal Health History Form** with as much information as you have gathered. This form should be completed within 72 hours and uploaded to the CalREDIE electronic filing cabinet or submitted directly to DCDC via fax to 916-552-9725 or submit via secure email to charsey.porse@cdph.ca.gov.

The CDC Registry Maternal Health History Form can be found here:

<http://www.cdph.ca.gov/HealthInfo/discond/Documents/MaternalHealthHistoryForm.pdf>

3) **Inform your LHD MCAH Director about the pregnant Zika case** - The local MCAH program may be able to assist with provider communication and with resourcing for the family.

4) **Prepare for testing at delivery** – Approximately 1 month in advance of anticipated delivery date, contact the health care provider to ask about the planned delivery hospital and review testing that should be completed at the time of delivery. See “Evaluation and Follow-Up Procedures for Suspected Congenital Zika Virus Infection” on the CDPH Zika webpage for details:

<http://www.cdph.ca.gov/HealthInfo/discond/Documents/GuidanceforCongenitalZikaInfectionEvaluation.pdf>.

- When you become aware of the delivery hospital, please inform the California Zika Pregnancy Registry via email at: ZikaOutcomes@cdph.ca.gov. Also indicate the delivery hospital in the ‘notes’ section under the ‘Case Investigation’ tab in CalREDIE.

5) **Prepare for Follow-Up Data Collection** – Identify who within your LHD will be the Zika Pregnancy contact to the CDPH. Determine your preference for data collection, beyond the initial diagnosis and investigation and neonatal testing:

- The LHD will contact health care providers to complete data collection.
- CDPH to contact health care providers to complete data collection.

Send your LHD Zika Pregnancy contact’s information and your data collection preference (LHD or CDPH) to ZikaOutcomes@cdph.ca.gov.

6) Complete and Submit Data Forms

The US Zika Pregnancy Registry data collection points include: the time of maternal diagnosis (# 2 above), 2nd trimester, 3rd trimester, delivery, and infant follow-up at 2, 6, and 12 months.

CDC forms include:

- Maternal Health History Form
<http://www.cdph.ca.gov/HealthInfo/discond/Documents/MaternalHealthHistoryForm.pdf>
- Infant Follow Up
<http://www.cdph.ca.gov/HealthInfo/discond/Documents/InfantFollowUpForm.pdf>
- Supplemental Imaging Form
<http://www.cdph.ca.gov/HealthInfo/discond/Documents/SupplementalMaternalPrenatalImagingDiagnosticsForm.pdf> (To be used when extra space is needed to record diagnostics, etc.)

- The Neonate Assessment Form will be completed by the CBDMP abstractors.
- Uploading forms to CalREDIE is the preferred method for submission to CDPH.
- If you are a CalREDIE non-participating jurisdiction, you may send the forms via SECURE email (call for instructions before sending: 510-620-3151) to the following address:
ZikaOutcomes@cdph.ca.gov

If faxing or emailing, **please remember to call or email for instructions before faxing or submitting any forms to CDPH**, so that we can ensure the privacy and security of all documents. Send additional inquiries to ZikaOutcomes@cdph.ca.gov.

Frequently Asked Questions

Is this case management? No

Are we contacting providers to request they do additional testing in order to complete the forms?

No, data collection for the US Zika Pregnancy Registry is intended to capture information already existing in the medical record.

What authority do we have to do this data collection?

- HIPAA Privacy Rule permits providers to disclose PHI without authorization to public health authorities for the purposes of preventing or controlling disease.
- CDC has received authorization for 308(d) Assurance of Confidentiality Protection for “surveillance of pregnancy and infant outcomes following Zika virus infections in Zika surveillance-related data” from the CDC Office of the Associate Director for Science.
- CDC has received a non-research determination from the National Center for Emerging and Zoonotic Infectious Diseases IRB.
- General powers of the Department to investigate causes of morbidity and mortality (H&S section 100325)
- The US Zika Pregnancy Registry is consistent with the purpose of the California Birth Defects Monitoring Program (CBDMP) to conduct studies to investigate the causes of birth defects, stillbirths, and miscarriages and to determine and evaluate measures designed to prevent their occurrence (H&S section 103840).