



# US Zika Pregnancy Registry



## Pediatric Healthcare Providers: How to Contribute

Zika virus infection during pregnancy has been linked to adverse outcomes, including pregnancy loss and microcephaly, absent or poorly developed brain structures, defects of the eye, and impaired growth in fetuses and infants. Despite these observations, very little is known about the risks of Zika virus infection to infants. More information about the timing, absolute risk, and spectrum of outcomes associated with Zika virus infection among infants is needed to direct public health action related to Zika virus and guide testing, evaluation, and management of pregnant women and infants exposed to Zika virus.

### US Zika Pregnancy Registry

To understand more about Zika virus infection, CDC established the US Zika Pregnancy Registry and is collaborating with state, tribal, local, and territorial health departments to collect information about pregnancy and infant outcomes following Zika virus infection during pregnancy. The data collected through this registry will provide more comprehensive information to complement notifiable disease case reporting and will be used to update recommendations for clinical care, to plan for services for pregnant women, children, and families affected by Zika virus, and to help prevent Zika virus infection during pregnancy.

### How to Participate

CDC and state, tribal, local, and territorial health departments request that pediatric healthcare providers participate in the US Zika Pregnancy Registry by:

1. Identifying and reporting suspected congenital Zika virus exposure in infants to their state, tribal, local, or territorial health department for possible testing.
2. Collecting pertinent clinical information about infants born to women with laboratory evidence of Zika virus infection or infants with congenital Zika virus infection.
3. Providing the information to state, tribal, local or territorial health departments or directly to CDC registry staff if asked to do so by local health officials.
4. Notifying state, tribal, local, or territorial health department staff or CDC registry staff of adverse events (e.g., perinatal or infant deaths).

### Who Is Included in the Registry

Cases in infants are eligible for inclusion in the US Zika Pregnancy Registry if the infants are born in a US state or territory\* to a woman with laboratory evidence of Zika virus infection or if the infants have laboratory evidence of congenital Zika virus infection (e.g., detection of Zika virus or Zika virus nucleic acids in a placental, fetal or neonatal specimen, or serologic evidence of Zika virus in serum or cerebral-spinal fluid).

Some infants who meet the above criteria will have been identified prenatally and reported to the health department in accordance with applicable state, tribal, local and territorial laws supporting notifiable disease surveillance. However, pediatric healthcare providers may also identify previously unrecognized cases of congenital Zika virus infection or prenatally or

perinatally exposed infants. These cases should be reported to the state, tribal, local, or territorial health department and are eligible to be included as new cases for the US Zika Registry. The US Zika Pregnancy Registry will collect supplemental surveillance information from routine medical care of women through pregnancy and infants through the first year of life.

Healthcare providers practicing in Puerto Rico should report eligible cases to the Puerto Rico Zika Active Pregnancy Surveillance System (ZAPSS) rather than to the US Zika Pregnancy Registry.\*

\*Puerto Rico is establishing a separate Zika Active Pregnancy Surveillance System (ZAPSS).

### **How To Report to the Registry**

- Healthcare providers who suspect congenital Zika virus infection in an infant should contact their state, tribal, local, or territorial health department if the infant meets the clinical criteria for testing as outlined in the CDC guidelines. The state, tribal, local, or territorial health department can facilitate laboratory testing for Zika virus infection in infants who meet these clinical criteria.
- Healthcare providers can contact the CDC Zika Pregnancy Hotline (available through CDC's Emergency Operations Center watch desk at 770-488-7100, [ZikaMCH@cdc.gov](mailto:ZikaMCH@cdc.gov) or [ZikaPregnancy@cdc.gov](mailto:ZikaPregnancy@cdc.gov) or fax 404-718-2200) to discuss suspected cases of congenital Zika virus infection. If healthcare providers contact CDC for clinical consultation, registry staff will ensure that state, tribal, local, or territorial health departments are promptly notified.

### **How the Data are Collected**

The registry will collect information about the infant at birth and at 2, 6, and 12 months of age. The information collected includes birth history and findings from physical, developmental, imaging, and laboratory assessments performed during clinical care of the infant. Depending on the preference of the state, tribal, local, or territorial health department, either health department staff or CDC registry staff will contact clinicians caring for infants with congenital Zika virus exposure or infection for data collection.

CDC is requesting the collection of clinical information in identifiable form as a public health authority. As defined in the Health Insurance Portability and Accountability Act (HIPAA) and its implementing regulations, Standards for Privacy of Individually Identifiable Health Information (45 CFR § 164.501)] ("Privacy Rule"), covered entities (e.g., healthcare providers) may disclose protected health information without patient authorization to a public health authority that is authorized by law to collect or receive such information for the purpose of preventing or controlling disease (42 CFR 164.512. ). Data to be collected include clinical information pertaining to results from evaluation and testing conducted at birth, and clinical/developmental information from the infant through the first year of life. As established in the HIPAA Privacy Rule (45 CFR 164.522, 164.524, 164.526, and 164.528), individuals have the right to request from covered entities (i.e., you, the healthcare provider) disclosing their PHI certain restrictions, access, amendments, and accounting of the disclosures of their protected health information.

### **More Information about Zika**

For more information or to contact CDC registry staff, call the CDC Emergency Operations Center watch desk at 770-488-7100 and ask for the Zika Pregnancy Hotline or email [ZikaMCH@cdc.gov](mailto:ZikaMCH@cdc.gov) or [ZikaPregnancy@cdc.gov](mailto:ZikaPregnancy@cdc.gov). More information on caring for infants or children with Zika virus infection is available at <http://www.cdc.gov/zika/hc-providers/index.html>.

### **CDC Guidance Materials**

1. Interim Guidance for Health Care Providers Caring for Women of Reproductive Age with Possible Zika Virus Exposure — United States, 2016 (Apr. 1, 2016)  
[http://www.cdc.gov/mmwr/volumes/65/wr/mm6512e2.htm?s\\_cid=mm6512e2\\_e](http://www.cdc.gov/mmwr/volumes/65/wr/mm6512e2.htm?s_cid=mm6512e2_e)
2. Interim Guidelines for Healthcare Providers Caring for Infants and Children with Possible Zika Virus Infection - United States, February 2016 (Feb. 19, 2016)  
<http://www.cdc.gov/mmwr/volumes/65/wr/mm6507e1.htm>
3. Zika Virus: Collection and Submission of Fetal Tissues for Zika Virus Testing  
<http://www.cdc.gov/zika/hc-providers/tissue-collection-submission.html>
4. Collection and Submission of Body Fluids for Zika Virus Testing <http://www.cdc.gov/zika/hc-providers/body-fluids-collection-submission.html>

**Thank you for your interest and participation in the US Zika Pregnancy Registry.**