

## United States Zika Pregnancy Registry (USZPR)



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**National Web Site:** <https://www.cdc.gov/pregnancy/zika/research/registry.html>

### **Source of Information for the Database**

In 2016, the Centers for Disease Control and Prevention (CDC) established the United States Zika Pregnancy Registry (USZPR) to learn more about the effects of Zika virus during pregnancy and on the growth and development of infants born to infected mothers. In collaboration with state, tribal, local, and territorial health departments, the CDC is collecting information on pregnancy and infant outcomes for all mother-baby pairs who meet inclusion criteria. Pregnant women with laboratory evidence of Zika virus infection and periconceptionally, prenatally, or perinatally exposed infants born to these women as well as infants with laboratory evidence of congenital Zika virus infection and their mothers are eligible for inclusion. The inclusion of infants who appear healthy is important because the short-term and long-term effects of in utero exposure to Zika virus are unknown. Enrollment in the USZPR will close on March 31, 2018; no pregnancies completed after this date will be included.

Data are collected by state and local health agencies, including the Kentucky Department for Public Health, and submitted to CDC. Various methods, including medical record abstraction and telephone consultation, are used to collect surveillance data with CDC's standardized data collection forms at appropriate, pre-determined time intervals. Within the KDPH, the Division of Epidemiology and Health Planning and the Division of Maternal and Child Health are collaborating for the USZPR, including coordinating Zika virus testing, ensuring data collection and reporting to CDC, providing guidance and support to healthcare providers and birthing facilities, and ensuring referrals to specialty and early intervention services for infants.

### **Description of the Data Collected**

The USZPR utilizes three primary data collection tools to obtain information about mother-baby pairs: the maternal health history form, the neonatal assessment form, and the infant follow-up form. The maternal health history form is completed at the time of the positive test result and at the end of each trimester; this form collects the following: demographic information, Zika virus history, exposure history, maternal health history, pregnancy information, and prenatal imaging and diagnostic results. The neonatal assessment form is completed around the time of delivery; this form collects the following: demographic information, physical examination, imaging and diagnostic results, and postnatal infection and cytogenetic testing results. The infant follow-up form is completed at 2, 6, and 12 months of age; the form collects the following: demographic information, weight, length, head circumference, and abnormal clinical findings.

### **Strengths of the Data**

The USZPR allows for real-time, population-based monitoring of all mother-baby pairs who meet eligibility criteria. Collection protocols and formats follow national, standardized guidelines. Aggregate data are available online and are updated twice per month.

### **Data Limitations**

Some data limitations should be considered when reviewing findings from the USZPR. Only pregnant women or infants who are tested for Zika virus infection and reported to the USZPR are included. The USZPR will therefore reflect reported Zika virus infection and outcomes and could underestimate infection and outcomes to the extent that these are not reported. The USZPR is not designed to determine whether poor pregnancy outcomes in women who had possible Zika virus infection during pregnancy were caused by Zika virus or other factors.

### **Specific Uses of Information**

It can be used to enhance knowledge about Zika virus in pregnancy in Kentucky and in the United States.

Contribute data to the CDC and Prevention in order to:

- Provide aggregate national estimates of pregnancies with laboratory evidence of possible Zika virus infection.
- Improve understanding of the impact of Zika virus infection on pregnancy and infant outcomes,
- Inform recommendations for clinical care.
- Plan services for pregnant women and families affected by Zika virus.
- Improve prevention of Zika virus infection during pregnancy.

### **System Evaluation**

Kentucky data are reviewed quarterly through a data completeness report conducted and distributed by CDC, providing metrics on the timeliness and completeness of data points for all three types of reporting forms. Additionally, informal review occurs each time subsequent forms of the same type are completed; data are compared with what has previously been reported about the case.

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### **Data Set Availability**

CDC provides aggregated data for the United States based on the USZPR.

### **Data Release Policy**

Kentucky-specific USZPR data are submitted to CDC for aggregate publication. State-level counts may be released in accordance with the minimum criteria found in the Kentucky Department for Public Health Data Release Policy.

### **Data Publications**

The cumulative number of pregnant women enrolled in the USZPR is reported on the CDC website twice per month:

<https://www.cdc.gov/zika/reporting/pregwomen-uscases.html>.

CDC also reports poor outcomes of pregnancy among women with laboratory evidence of Zika virus infection twice per month, including live born infants with birth defects and pregnancy losses with birth defects:

<https://www.cdc.gov/zika/reporting/pregnancy-outcomes.html>.

Additionally, publications using USZPR data are available online, including: Update on Zika Virus-Associated Birth Defects and Evaluation of All U.S. Infants with Congenital Zika Virus Exposure – U.S. Zika Pregnancy Registry, 2016:

[https://www.cdc.gov/mmwr/volumes/66/wr/mm6613e1.htm?s\\_cid=mm6613e1\\_w](https://www.cdc.gov/mmwr/volumes/66/wr/mm6613e1.htm?s_cid=mm6613e1_w)

### **Suggested Data Citation**

Kentucky Department for Public Health (KDPH) and Centers for Disease Control and Prevention (CDC). United States Zika Pregnancy Registry. Frankfort, Kentucky: Cabinet for Family and Health Services, Kentucky Department for Public Health, [data year].

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