

The U.S. Zika Pregnancy & Infant Registry



Answering Questions about Infants born to Mothers with Possible Zika Virus Infection during Pregnancy

The U.S. Zika Pregnancy and Infant Registry is a collaborative and innovative system to help us learn about the effects of possible Zika virus infection during pregnancy and how this affects an infant at birth and in the first few years of life.

The Problem:

Zika virus is a new health threat, and we still know very little about how it affects the growth and development of children infected with the virus before birth.

The Solution:

Since early 2016, we used the U.S. Zika Pregnancy & Infant Registry (“the Registry”) to collect medical information about pregnant women with laboratory evidence of possible Zika virus infection and their infants. We continue to use this information to work with health departments and healthcare providers to better understand how Zika virus infection during pregnancy affects these infants. This will ultimately help health departments and healthcare providers connect more families to services they need. To accomplish this goal, **we continue to need your help.**

For data collection, medical information is needed at these ages:



* For Puerto Rico, medical information is collected through 36 months of age.

How can you help?

The Registry will follow infants through **at least their second birthday** in as many states and territories as possible. To accomplish this goal, obstetricians should communicate with pediatricians caring for infants of affected mothers to ensure that Zika test results and other medical information are shared between doctors. This communication and collaboration will ensure the best care and consistent treatment for both the mother and infant. Information about infants born to mothers with possible Zika virus infection during pregnancy should be collected at their regular well-child visits, regardless of whether clinical findings related to Zika appear or not. These findings include microcephaly, eye abnormalities, central nervous system dysfunction, and others.



What we know because of the Registry:

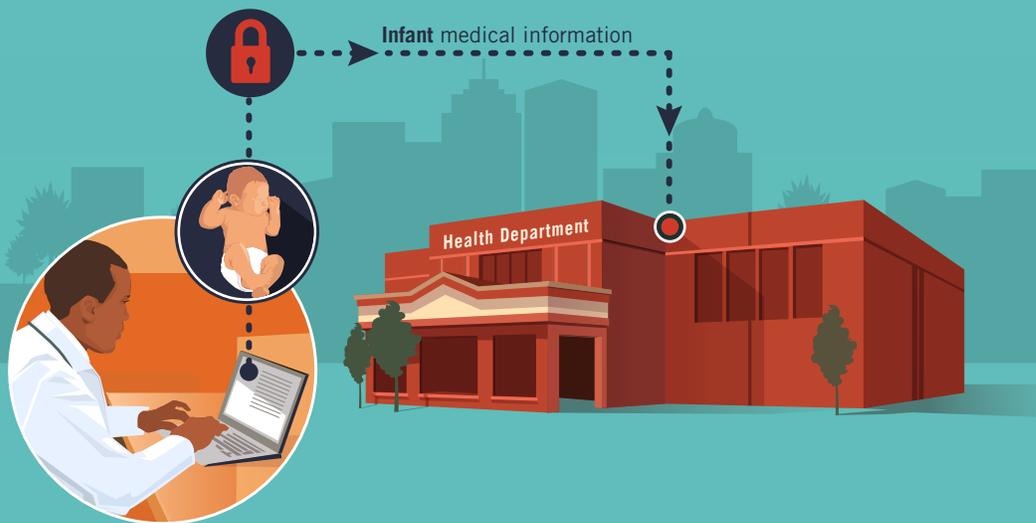
Since the Registry began in 2016, we have learned about Zika virus infection in mothers and their infants. Some of our findings include...

In U.S. States and D.C.,
1 in 10 infants

born to mothers with laboratory-confirmed Zika virus infection during pregnancy had Zika-associated birth defects

Confirmed Zika virus infections in the
1st trimester pose the highest risk
for Zika-associated birth defects

The proportion of infants with Zika-associated birth defects was similar for women who did and did not report
Zika-related symptoms
during pregnancy



Why should you collect medical information even if the infant appears healthy?

We know Zika virus infection during pregnancy causes adverse outcomes in infants. Specialized tests are needed for early detection of even slight changes in an infant's growth or development. By recording these findings, we can study Zika virus on a larger scale to better understand its health effects, update clinical guidance, and plan for services needed to protect all infants affected.

At each of these visits, pediatricians should follow these steps for optimal infant care:

- 1 Follow [CDC's Updated Guidance](#) for infants with possible Zika virus infection during each visit by assessing growth and development and performing additional hearing, vision, and other tests as indicated.
- 2 Reassure mothers that their infant's and their own identity and medical information will be kept private and protected under an Assurance of Confidentiality.
- 3 Securely share the information from each infant's visit with their state, tribal, local, or territorial health department.

Once health department officials receive the medical information, they securely send us the information for

- Rapid data analysis
- Clinical review
- Reporting of the total number of adverse outcomes
- Dissemination of findings

More Resources to Help Infants Born to Mothers with Zika

For additional resources visit the CDC website, www.cdc.gov/pregnancy/zika.

To contact us to learn how to **securely** send medical information regarding Zika virus infection, call 1-800-CDC-INFO.

“ Our pregnancy and birth defects surveillance systems are a **collaborative effort** with state, tribal, local, and territorial health departments and are **essential for protecting mothers and babies** affected by Zika virus.”

- Margaret (Peggy) Honein, PhD, MPH, Director of the Division of Congenital and Developmental Disorders

Over 7,400 pregnancies with laboratory evidence of possible Zika virus infection in US states and territories have been reported to the Registry as of October 2018.



cdc.gov/pregnancy/zika