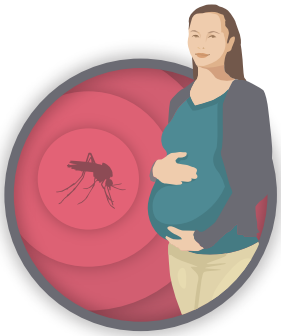
CDC's Response to **Zika**

US Zika Pregnancy Registry

What Parents Need to Know



What is the purpose of the registry?

CDC developed the US Zika Pregnancy Registry to:

- Learn more about the effects of Zika virus infection (Zika) during pregnancy.
- Learn more about the growth and development of babies whose mothers had Zika while pregnant.

CDC will collect health information about Zikapregnant women and babies across the United States for the registry. CDC, health departments, doctors and healthcare providers will use the information from this registry to help pregnant women, children, and families affected by Zika.

Who is being included in the registry?

Women living in the United States who may have been infected with Zika during pregnancy (but did not necessarily show symptoms of Zika) and their babies can be included in the registry. Puerto Rico is establishing a separate Zika Active Pregnancy Surveillance System (ZAPSS).

What will be done with the information collected?

The identity of people in the registry will be kept private and secure. The information your child's doctor or other healthcare provider shares will be added to the registry of information about pregnant patients with Zika, and the babies born to these women. The information in the registry will help CDC and state health departments develop a clearer picture of how Zika affects pregnant women and their babies.

What do I have to do to be in the registry?

You and your child will not need to do extra paperwork, go to extra appointments, or have extra tests to be part of the registry. If your child's healthcare provider is participating in this registry, they will share information about your child's health with the health department and CDC, the federal public health authority that is working to understand, prevent, and control Zika. The health department and CDC will work with your child's doctor and other healthcare providers to collect all the information needed.

For this registry, CDC and the health department will

- Collect information about your child's birth
- Collect information about your child's growth and development up to his or her first birthday
- Collect information about the mother of your child

If your child changes doctors or healthcare providers, please ask the new healthcare provider to contact registry staff through the email address below.

As established in the HIPAA Privacy Rule (45 CFR 164.528), you have the right to request from your child's healthcare provider an accounting of the disclosure of your protected health information at any time.

How much does this cost?

Being in the registry will not cost you any money.

www.cdc.gov/zika

What if I have questions?

For more information about the registry, visit CDC's registry webpage (www.cdc.gov/zika/hc-providers/registry.html) or contact CDC-INFO by calling 800-232-4636 (TTY 888-232-6348) or submitting an online inquiry (wwwn.cdc.gov/dcs/ContactUs/Form). If you have questions about testing for Zika virus, please contact your healthcare provider.

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