# US ZIKA PREGNANCY REGISTRY WHAT PREGNANT WOMEN 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 Zika among pregnant 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?

Pregnant women in the United States and US territories (except for Puerto Rico) with laboratory evidence of possible Zika virus infection (regardless of whether they have symptoms) and their babies can be included in the Registry. Puerto Rico has established a separate Zika Active Pregnancy Surveillance System (ZAPSS).

#### What will be done with the information collected?

The information your doctor or other healthcare provider shares will be added to the Registry with information about other pregnant patients with Zika, and the babies born to these mothers, to help CDC and health departments develop a clearer understanding of how Zika affects pregnant women and their babies. CDC has obtained an Assurance of Confidentiality to protect the information in this registry that could identify you or your baby. CDC cannot share this information with anyone without your permission, even if an official of the court, government, or law requests it.

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

You will not need to do extra paperwork, go to extra appointments, or have extra tests to be part of the Registry. If your healthcare provider is participating in this Registry, she/he will share information about your health with your health department and the CDC. Your health department and CDC will work with your doctor and other healthcare providers to collect all of the information needed. For this Registry, your health department and CDC will:

- · Collect information about your pregnancy,
- Collect information about you and your baby around the time the baby is born, and
- Contact the baby's doctor or other healthcare provider to collect information about the baby's growth and development up to his or her first birthday.

If you change doctors or healthcare providers, please refer the new healthcare providers to CDC's US Zika Pregnancy Registry webpage.

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

# 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 infection, please contact your healthcare provider.
- If you would like to speak to someone about a possible
   Zika virus infection or diagnosis during pregnancy,
   Mother to Baby experts are available to answer questions
   in English or Spanish by phone, email, or chat
   (www.MotherToBaby.org). The free, confidential service is
   available Monday Friday from 8am 5pm (local time).

#### How much does this cost?

Being in the Registry will not cost you any money.

