

# **CDC US ZIKA PREGNANCY REGISTRY**

## HEALTHCARE PROVIDER TOOLKIT FOR HEALTH DEPARTMENTS

**FOR PEDIATRICIANS**



CENTERS FOR DISEASE CONTROL AND PREVENTION  
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**U.S. Department of  
Health and Human Services**  
Centers for Disease  
Control and Prevention

## Welcome

The success of the US Zika Pregnancy Registry (USZPR) depends on the voluntary collaboration of healthcare workers and local health departments to report complete and accurate case information. This toolkit is a suite of tools and resources to help health departments educate and inform healthcare providers to identify, counsel, report, and follow infants born to pregnant women with laboratory evidence of Zika virus infection. We invite you to use this toolkit to raise awareness about the USZPR and improve reporting and completeness of data collected.

The USZPR was established in collaboration with state, tribal, local, and territorial health departments to collect information about pregnancy and infant outcomes following Zika virus infection during pregnancy. This information will be used to update recommendations for clinical care, to plan for services for pregnant women and families affected by Zika virus, and to improve prevention of Zika virus infection during pregnancy.

We hope you find these materials useful.

If you have any further questions, please email [zikapregnancy@cdc.gov](mailto:zikapregnancy@cdc.gov).

## Using Materials in this Toolkit

This toolkit includes materials to assist pediatricians with **Identification, Diagnosis, and Reporting** of congenital Zika virus infection in infants. All factsheets and infographics can be printed, shared, and distributed as needed. The following materials are included in this toolkit:

- **Identification:** These materials can assist providers with recognizing potential Zika virus cases.
  - Infant Guidance: Clinical guidance is available to provide pediatricians with up-to-date information about testing, initial evaluation, and clinical management among infants infected with Zika during pregnancy.
  - Measuring Head Circumference Factsheet: This resource describes how to measure an infant's head circumference.
- **Diagnosis:** These materials can assist providers with diagnostic testing to determine if an infant is infected with Zika virus and provide counseling to expectant parents.
  - Pocket Guide - Initial Evaluation and Outpatient Management for Infants with Zika: This resource can be used to evaluate infants with possible congenital Zika virus infection during the first 12 months of life.
  - Specimen Collection Factsheets: These resources provide detailed information on what type of specimens to test, how, when and why to test, and storage and shipping instructions.
    - For collection and submission of specimens at time of birth
    - For collection and submission of fetal tissue
  - Assessment of Infant Hearing: This resource is to guide hearing assessments for infants testing positive for Zika virus infection.
  - “What to Know” Factsheets for Families: These materials can assist pediatricians with conversations about congenital abnormalities and tracking infant development.
    - If your baby was born with Congenital Zika Syndrome
    - If your baby may have been affected by Zika but has no related health conditions at birth
- **Reporting:** These materials can assist with improved reporting of pregnancy and birth defects data.
  - Registry Factsheet for Pediatricians: This resource describes who should be included in the registry and how pediatricians can report case information.
  - Registry Factsheet for Parents: This resource describes the purpose and criteria of the registry.
- **Additional resources:** Available to guide providers to supplemental information.

# INTRODUCTION

Dear [Pediatric Healthcare Provider/Practice],

As you know, Zika virus infection during pregnancy can cause microcephaly and other severe brain defects and has been linked to a number of other adverse pregnancy outcomes. The Centers for Disease Control and Prevention (CDC) US Zika Pregnancy Registry seeks to track all pregnancies with laboratory evidence of possible Zika virus infection, whether or not the mother has symptoms.

The goals of the US Zika Pregnancy Registry are to obtain the information CDC needs to estimate the risk of congenital infection among fetuses and infants of pregnant women with possible Zika infection and to identify factors that may influence infant development. This information will be used to update clinical guidance, plan for services for pregnant women and infants affected by Zika virus, and improve prevention of Zika virus infection during pregnancy.

### **Healthcare Providers' Roles**

You can help. As your [state, tribal, local, or territorial health department], we may contact your practice to request routine 2, 6, and 12 month health examinations for infants with possible congenital Zika virus exposure (whether or not congenital Zika virus disease is confirmed). The information requested represents the minimum necessary to carry out the public health purposes of the US Zika Pregnancy Registry.

### **Patient Confidentiality**

As a healthcare provider, you are considered a covered entity under the Health Insurance Portability and Accountability Act (HIPAA). Under the HIPAA Privacy Rule (45 CFR § 164.501), you may disclose, without prior authorization, protected health information to public health authorities, such as CDC, which are authorized by section 301 of the Public Health Service Act to collect or receive identifiable information for the purpose of preventing or controlling disease. However, per federal standards established in the HIPAA Privacy Rule, people have the right to receive an accounting of disclosures of their protected health information made by a covered entity.

CDC has developed fact sheets that you may wish to give to your patients to let them know how their information is being used: <http://www.cdc.gov/zika/hc-providers/registry.html>. These fact sheets also contain information on the Assurance of Confidentiality that CDC has obtained. This Assurance is a formal confidentiality protection authorized under Section 308(d) of the Public Service Act that stipulates that CDC cannot be compelled to release protected health information for any reason without authorization from you and your patient. Because of this Assurance, information collected for the US Zika Pregnancy Registry may only be used to better understand Zika virus infection during pregnancy and its outcomes.

### **Resources**

We appreciate your time and attention to this important public health issue. For up-to-date tools and resources, please visit the US Zika Pregnancy Registry Healthcare Provider website, <https://www.cdc.gov/zika/reporting/registry.html>. This website includes patient checklists, trainings for healthcare providers, clinical guidance, print-ready counseling resources, and other helpful tips.

**[Insert appropriate jurisdiction signature]**

## IDENTIFICATION

## Update: Interim Guidance for the Evaluation and Management of Infants with Possible Congenital Zika Virus Infection — United States, August 2016

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*On August 19, 2016, this report was posted as an MMWR Early Release on the MMWR website (<http://www.cdc.gov/mmwr>).*

CDC has updated its interim guidance for U.S. health care providers caring for infants born to mothers with possible Zika virus infection during pregnancy (1). Laboratory testing is recommended for 1) infants born to mothers with laboratory evidence of Zika virus infection during pregnancy and 2) infants who have abnormal clinical or neuroimaging findings suggestive of congenital Zika syndrome and a maternal epidemiologic link suggesting possible transmission, regardless of maternal Zika virus test results. Congenital Zika syndrome is a recently recognized pattern of congenital anomalies associated with Zika virus infection during pregnancy that includes microcephaly, intracranial calcifications or other brain anomalies, or eye anomalies, among others (2). Recommended infant laboratory evaluation includes both molecular (real-time reverse transcription–polymerase chain reaction [rRT-PCR]) and serologic (immunoglobulin M [IgM]) testing. Initial samples should be collected directly from the infant in the first 2 days of life, if possible; testing of cord blood is not recommended. A positive infant serum or urine rRT-PCR test result confirms congenital Zika virus infection. Positive Zika virus IgM testing, with a negative rRT-PCR result, indicates probable congenital Zika virus infection. In addition to infant Zika virus testing, initial evaluation of all infants born to mothers with laboratory evidence of Zika virus infection during pregnancy should include a comprehensive physical examination, including a neurologic examination, postnatal head ultrasound, and standard newborn hearing screen. Infants with laboratory evidence of congenital Zika virus infection should have a comprehensive ophthalmologic exam and hearing assessment by auditory brainstem response (ABR) testing before 1 month of age. Recommendations for follow-up of infants with laboratory evidence of congenital Zika virus infection depend on whether abnormalities consistent with congenital Zika syndrome are present. Infants with abnormalities consistent with congenital Zika syndrome should have a coordinated evaluation by multiple specialists within the first month of life; additional evaluations will be needed within the first year of life, including assessments of vision, hearing, feeding, growth, and neurodevelopmental and endocrine function. Families and caregivers will also need

ongoing psychosocial support and assistance with coordination of care. Infants with laboratory evidence of congenital Zika virus infection without apparent abnormalities should have ongoing developmental monitoring and screening by the primary care provider; repeat hearing testing is recommended. This guidance will be updated when additional information becomes available.

Zika virus infection during pregnancy is a cause of microcephaly and other serious brain anomalies (3); however, the clinical spectrum of the effects of Zika virus infection during pregnancy is not yet known. A wide range of neurologic abnormalities, in addition to microcephaly, has been observed among infants with presumed or confirmed congenital Zika virus infection (2,4). Reported neuroimaging findings include intracranial calcifications; ventriculomegaly and extra-axial fluid; abnormal gyral patterns (e.g., polymicrogyria); decreased brain parenchymal volume; cortical atrophy and malformation; hypoplasia of the cerebellum, cerebellar vermis or brainstem; delayed myelination; and thinning or hypoplasia of the corpus callosum (5,6). Neurologic abnormalities apparent on examination of these infants have included hypertonia, hypotonia, spasticity, hyperreflexia, severe irritability, and seizures (2,4). Zika virus appears to primarily target neural progenitor cells resulting in cell death and disruption of neuronal proliferation, migration and differentiation, which slows brain growth and affects neural cell viability (7–9). Ocular findings reported in infants with presumed or confirmed congenital Zika virus infection have included chorioretinal atrophy or scarring, pigmentary changes, optic nerve hypoplasia, optic disc pallor, increased optic disc cupping, hemorrhagic retinopathy and abnormal retinal vasculature (10–12). Some infants with presumed or confirmed congenital Zika virus infection have had a phenotype consistent with fetal brain disruption sequence, characterized by severe microcephaly, collapse of the skull, overlapping cranial sutures, prominent occipital bone, redundant scalp skin, and severe neurologic impairment (13,14). Other findings seen in infants with congenital Zika virus infection have included clubfoot and contractures of single or multiple joints (arthrogryposis), presumably secondary to central nervous system damage (4).

Experience with other congenital infections can provide insight to guide clinical management until more data emerge

regarding outcomes associated with congenital Zika virus infection. Infants with congenital infections, such as cytomegalovirus (CMV) and rubella, can develop a range of clinical manifestations, including hearing loss, seizures, neurodevelopmental delays and diabetes mellitus later in life (15,16), even without apparent clinical manifestations of congenital infection at birth (17).

Diagnostic testing for congenital Zika virus infection can be challenging. Whereas a positive molecular (rRT-PCR) testing result in an infant can confirm Zika virus infection, a negative result does not exclude infection. Viral shedding can be prolonged in congenital CMV and rubella infections (18,19); however, little is known about the duration of viral shedding in infants with congenital Zika virus infection. IgM results might assist in making the diagnosis, but can be difficult to interpret because of false-positive results occurring from cross-reacting IgM antibodies or nonspecific reactivity (20). Because maternal IgG crosses the placenta, the presence of IgG in an infant specimen cannot be used as evidence of congenital infection.

Currently, there are >1,000 pregnant women with laboratory evidence of possible Zika virus infection in the United States and U.S. territories (<http://www.cdc.gov/zika/geo/pregwomen-uscases.html>). Pediatric health care providers need information to guide appropriate laboratory testing and clinical evaluation and management of infants born to these mothers. On July 21–22, 2016, CDC, in collaboration with the American Academy of Pediatrics (AAP), convened a meeting to obtain individual input from experts and partners to inform the development of guidance for the evaluation and management of infants with congenital Zika virus infection. In attendance were experts in pediatrics, infectious diseases, neurology, developmental and behavioral pediatrics, ophthalmology, audiology, physical medicine and rehabilitation, neonatology, lactation and nutrition, maternal-fetal medicine, clinical genetics, hospitalist medicine, neonatology, and endocrinology, and representatives from principal partner groups (Box 1). Discussion focused on three areas: 1) initial evaluation and laboratory testing of infants born to mothers with laboratory evidence of Zika virus infection during pregnancy, 2) outpatient management and follow-up of infants with microcephaly or other findings consistent with congenital Zika syndrome, and 3) outpatient management and follow-up of infants with laboratory evidence of congenital Zika virus infection but without findings consistent with congenital Zika syndrome.

This guidance aims to assist health care providers in the evaluation and management of infants with congenital Zika virus infection based on currently available data on congenital infections with Zika virus and other pathogens. As more information becomes available, this guidance will be updated.

## Updated Recommendations for the Initial Laboratory Testing and Evaluation of Infants with Possible Congenital Zika Virus Infection

**Infant diagnostic testing.** Laboratory testing for congenital Zika virus infection is recommended for infants born to mothers with laboratory evidence of Zika virus infection, and for infants with findings suggestive of congenital Zika syndrome and a maternal epidemiologic link suggesting possible transmission, regardless of maternal testing results (Figure). Laboratory evidence of maternal Zika virus infection includes Zika virus RNA detected in any maternal clinical specimen by rRT-PCR and positive Zika virus IgM with confirmatory neutralizing antibody titer for Zika virus or flavivirus, not otherwise specified. Zika virus rRT-PCR testing should be performed on both infant serum and urine, and Zika virus IgM enzyme-linked immunosorbent assay (ELISA) should concurrently be performed on infant serum. If cerebrospinal fluid (CSF) is obtained for other studies, rRT-PCR testing for Zika virus RNA and Zika virus IgM should be performed on CSF. Laboratory testing should be performed on infant specimens; cord blood is not recommended because it can yield false positive results through contamination with maternal blood and might also yield false negative results (21). Infant laboratory testing for Zika virus should be performed within the first 2 days after birth; if testing is performed later, distinguishing between congenital, perinatal, and postnatal infection will be difficult. If the timing of infection cannot be determined, infants should be managed as if they have congenital Zika virus infection.

A Zika rRT-PCR positive result in an infant sample confirms the diagnosis of congenital Zika virus infection (Table 1). Zika virus IgM detected in an infant, without detectable Zika virus RNA, should be interpreted as probable congenital Zika virus infection. The plaque reduction neutralization test (PRNT) measures virus-specific neutralizing antibodies and is used to confirm the specificity of the IgM antibodies against Zika virus and rule out a false positive IgM result (20). If the infant's initial sample is IgM-positive, but PRNT was not performed on the mother's sample, PRNT should be performed on the infant's initial sample. However, PRNT cannot distinguish between maternal and infant antibodies. Because of this, it might be necessary to wait until the child is at least age 18 months, when maternal antibodies are expected to wane, to confirm congenital infection. PRNT should be performed on a sample collected from a child aged  $\geq 18$  months whose initial sample was IgM positive if Zika-specific neutralizing antibodies were detected by PRNT on either the infant's or mother's sample. If the infant's initial sample is negative by both IgM ELISA and rRT-PCR but clinical concerns remain (e.g., microcephaly with negative evaluation for other known causes), PRNT at age



**BOX 1. Areas of expertise and organizations represented at the Clinical Evaluation and Management of Infants with Congenital Zika Virus Infection meeting — Atlanta, Georgia, July 21–22, 2016**

**Specialties represented**

Audiology  
 Clinical genetics  
 Critical care  
 Developmental and behavioral pediatrics  
 Endocrinology  
 Hospitalist medicine  
 Infectious disease  
 Lactation and infant feeding  
 Maternal-fetal medicine  
 Neonatology  
 Neurology  
 Nutrition  
 Ophthalmology  
 Orthopedics  
 Pediatrics  
 Physical medicine and rehabilitation

**Partner organizations**

American Academy of Family Physicians  
 American Academy of Pediatrics (including representation from the Puerto Rico chapter)  
 American College of Obstetricians and Gynecologists  
 Association of Maternal & Child Health Programs  
 Family Voices, Inc.  
 March of Dimes  
 National Association of Pediatric Nurse Practitioners  
 Parent to Parent of Georgia  
 Society for Maternal-Fetal Medicine

**Federal agencies**

Administration for Children and Families  
 CDC  
 Centers for Medicare & Medicaid Services  
 Maternal and Child Health Bureau, Health Resources and Services Administration  
 National Institute of Child Health and Human Development, National Institutes of Health  
 Office of the Assistant Secretary for Preparedness and Response

18 months can be considered. If PRNT results at 18 months are negative, the child is considered to not have congenital Zika virus infection. If PRNT results are positive, congenital Zika infection is presumed, but postnatal infection cannot be excluded, especially for children living in an area with active Zika virus transmission.

In many cases, infant laboratory testing results will not be available before hospital discharge. In these cases, infants should be presumed to have congenital Zika virus infection until test results are available. For the purposes of this guidance, infants with confirmed or probable Zika virus infection should be managed in the same manner.

Detection of Zika virus RNA in the placenta can confirm the presence of maternal infection, but cannot distinguish between maternal and congenital infection. For circumstances in which maternal testing was not previously performed, performed more than 12 weeks after exposure (22), or was not definitive (e.g., flavivirus not otherwise specified) (20), a positive placental rRT-PCR result can confirm maternal Zika virus infection. Based on unpublished CDC data, placentas from mothers with Zika virus infection during pregnancy can have detectable Zika virus RNA at the time of delivery, regardless of the timing of maternal infection. Clinical implications for an infant with Zika virus RNA detected in the placenta, in the absence of laboratory evidence of Zika virus in the infant, are unknown.

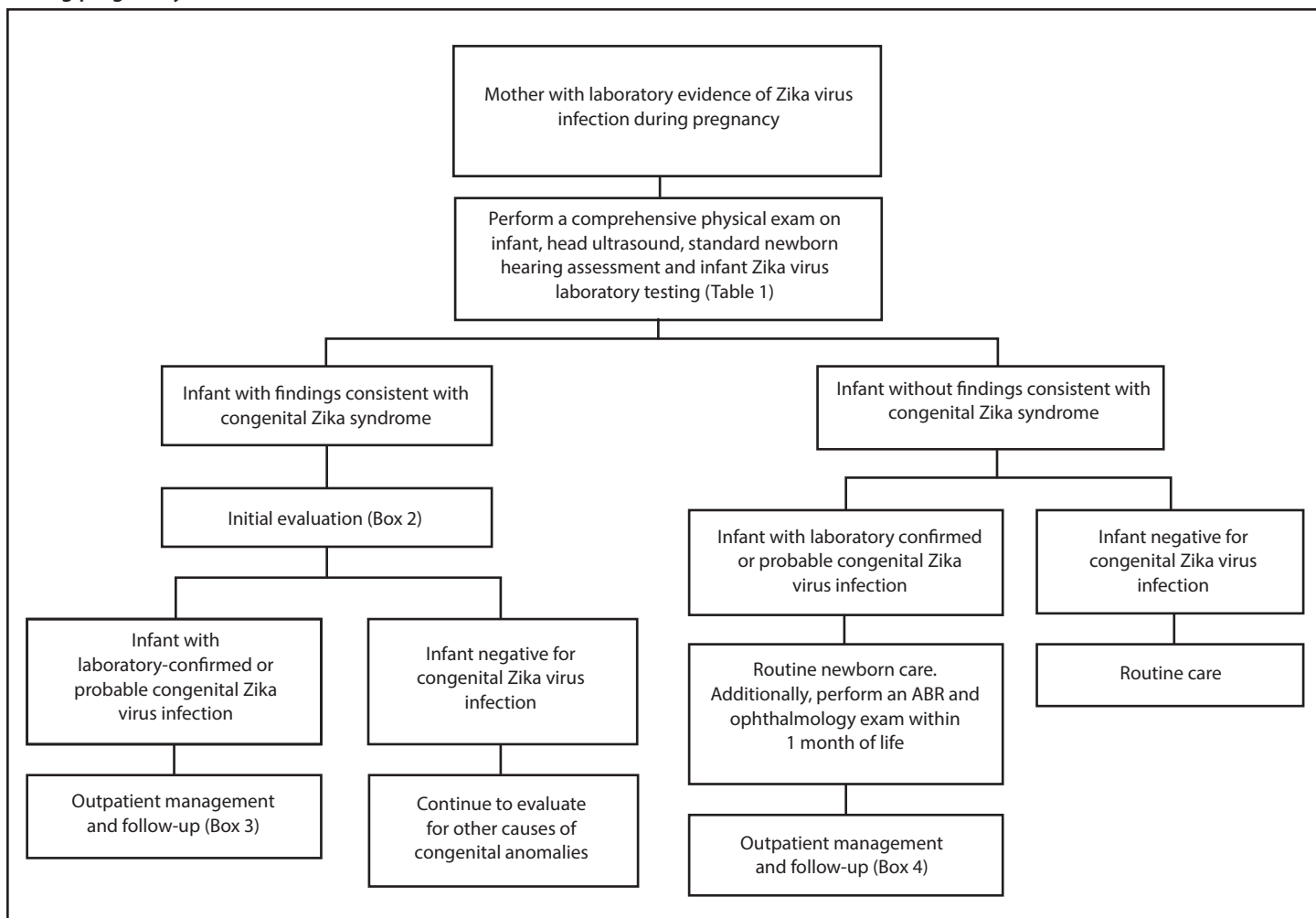
Limited data are currently available regarding perinatal Zika virus transmission (23). Guidelines for evaluation and management of infants and children with postnatally acquired Zika virus disease (1) will be updated as more information is available.

**Clinical evaluation of infants.** Infants born to mothers with laboratory evidence of Zika virus infection should receive a comprehensive physical examination, including precise measurement of head (occipitofrontal) circumference,\* length and weight, assessment of gestational age, and examination for neurologic abnormalities and dysmorphic features (Table 2). A postnatal head ultrasound should be performed on all infants born to mothers with laboratory evidence of Zika virus infection before discharge from the hospital, including those infants with normal prenatal ultrasound findings, because some abnormal findings associated with congenital Zika syndrome might not be readily apparent on prenatal ultrasounds. All infants should receive a hearing screen per universal screening recommendations before hospital discharge. Infants with laboratory evidence of congenital Zika virus infection should be referred for a comprehensive ophthalmologic exam and evaluation of hearing by ABR testing before 1 month of age. Other evaluations should be performed as clinically indicated.

Infants with negative IgM and negative rRT-PCR testing born to a mother with laboratory evidence of Zika virus

\* Standard head circumference charts are based on measurements taken within 24 hours of birth. Additional information on child growth standards is available at <http://www.who.int/childgrowth/en/>. Additional information on head circumference measurement is available at [https://www.cdc.gov/zika/pdfs/microcephaly\\_measuring.pdf](https://www.cdc.gov/zika/pdfs/microcephaly_measuring.pdf).

**FIGURE. Recommended Zika virus testing and evaluation of infants born to mothers with laboratory evidence of Zika virus infection during pregnancy \***



**Abbreviation:** ABR = auditory brainstem response.

\* Laboratory evidence of maternal Zika virus infection includes 1) Zika virus RNA detected by real-time reverse transcription–polymerase chain reaction (rRT-PCR) in any clinical specimen; or 2) positive Zika virus immunoglobulin M (IgM) with confirmatory neutralizing antibody titers. Mothers should be tested by rRT-PCR within 2 weeks of exposure or symptom onset, or by IgM within 2–12 weeks of exposure or symptom onset. Because of the decline in IgM antibody and viral RNA levels over time, negative maternal testing 12 weeks after exposure does not rule out maternal infection. **Source:** Oduyebo T, Igbinosa I, Petersen EE, et al. Update: interim guidance for health care providers caring for pregnant women with possible Zika virus exposure—United States, July 2016. *MMWR Morb Mortal Wkly Rep* 2016;65:739–44. <http://dx.doi.org/10.15585/mmwr.mm6529e1>.

**TABLE 1. Interpretation of results of laboratory testing of infant’s blood, urine and/or cerebrospinal fluid for evidence of congenital Zika virus infection**

| Infant test results* |                      |   |
|----------------------|----------------------|---|
| rRT-PCR              | IgM                  | Interpretation                                |
| Positive             | Positive or Negative | Confirmed congenital Zika virus infection     |
| Negative             | Positive             | Probable congenital Zika virus infection†     |
| Negative             | Negative             | Negative for congenital Zika virus infection† |

**Abbreviations:** rRT-PCR = real-time reverse transcription–polymerase chain reaction; IgM = immunoglobulin M.

\* Infant serum, urine, or cerebrospinal fluid.

† Laboratory results should be interpreted in the context of timing of infection during pregnancy, maternal serology results, clinical findings consistent with congenital Zika syndrome, and any confirmatory testing with plaque reduction neutralization testing (PRNT).

infection should receive routine care, including monitoring of head circumference at every well child visit and age-appropriate developmental screening (24). Health care providers should report information on pregnant women in the United States and the U.S. territories with laboratory evidence of Zika virus infection and their infants (regardless of infant test results) to state, tribal, local, or territorial health departments for inclusion in the U.S. Zika Pregnancy Registry (<http://www.cdc.gov/zika/hc-providers/registry.html>), or the Puerto Rico Zika Active Pregnancy Surveillance System (ZAPSS) (<http://www.cdc.gov/zika/public-health-partners/zapss.html>).

For all infants with abnormal findings consistent with congenital Zika syndrome, an extensive evaluation is recommended

**TABLE 2. Initial evaluation and recommended outpatient management during the first 12 months of life for infants with possible congenital Zika virus infection, based on maternal and infant laboratory tests and infant clinical findings**

| Mother   | Infant clinical exam                                   | Before hospital discharge  | Infant testing   | 2 wks.  | 1 mo. | 2 mos. | 3 mos. | 4–6 mos. | 9 mos. | 12 mos. |
|--|--|--|--|---|-------|--------|--------|----------|--------|---------|
| Laboratory evidence of Zika virus infection*         | No evidence of abnormalities                           | Routine newborn care: PE, HC, weight/length, and neurologic exam<br>Hearing screen<br>Head US<br>Infant Zika virus testing (Table 1)   | Negative for Zika virus infection<br><br>Laboratory evidence of Zika virus infection*        | Routine care, including monitoring of OFC and development at every well child visit and age-appropriate developmental screening |       |        |        |          |        |         |
|  | Abnormalities consistent with congenital Zika syndrome | As above plus:<br>Consider transfer to hospital with subspecialty care<br>CBC, metabolic panel, LFTs, ophthalmology exam<br>ABR<br>Consider advanced neuroimaging (Box 2)                                  | Negative for Zika virus infection<br><br>Laboratory evidence of Zika virus infection*        | Evaluate for other causes of congenital anomalies<br>Further management as clinically indicated                                 |       |        |        |          |        |         |
| Not tested, or tested outside of appropriate window† | No evidence of abnormalities                           | Maternal Zika virus testing†<br>Consider Zika virus placental testing<br>Routine newborn care: PE, HC, weight/length and neurologic exam<br>Hearing screen<br>Head US                                      | Perform infant Zika virus testing if evidence of Zika virus infection on maternal testing*,† | Outpatient management for appropriate infant clinical exam and test results   |       |        |        |          |        |         |
|  | Abnormalities consistent with congenital Zika syndrome | As above, plus:<br>Consider transfer to hospital with subspecialty care.<br>CBC, metabolic panel, LFTs, ophthalmology exam<br>ABR<br>Consider advanced neuroimaging<br>Infant Zika virus testing (Table 1) | Negative for Zika virus infection<br><br>Laboratory evidence of Zika virus infection*        | Evaluate for other causes of congenital anomalies<br>Further management as clinically indicated                                 |       |        |        |          |        |         |

**Abbreviations:** ABR = auditory brainstem response; CBC = complete blood count; LFTs = liver function tests; HC = head (occipitofrontal) circumference; PE = physical examination; rRT-PCR = real-time reverse transcription–polymerase chain reaction; US = ultrasound.

\* Laboratory evidence of maternal Zika virus infection includes 1) Zika virus RNA detected by real-time reverse transcription–polymerase chain reaction (rRT-PCR) in any clinical specimen; or 2) positive Zika virus immunoglobulin M (IgM) with confirmatory neutralizing antibody titers. Confirmatory neutralizing antibody titers are needed in addition to IgM for maternal Zika virus infection.

† Mothers should be tested by rRT-PCR within 2 weeks of exposure or symptom onset, or by IgM within 2–12 weeks of exposure or symptom onset. Because of the decline in IgM antibody titers and viral RNA levels over time, negative maternal testing 12 weeks after exposure does not rule out maternal infection. **Source:** Oduyebo T, Igbino I, Petersen EE, et al. Update: interim guidance for health care providers caring for pregnant women with possible Zika virus exposure—United States, July 2016. *MMWR Morb Mortal Wkly Rep* 2016;65:739–44. <http://dx.doi.org/10.15585/mmwr.mm6529e1>. Mothers should be tested by rRT-PCR within 2 weeks of exposure or symptom onset, or by IgM within 2–12 weeks of exposure or symptom onset. Because of the decline in IgM antibody titers and viral RNA levels over time, negative maternal testing 12 weeks after exposure does not rule out maternal infection. <http://dx.doi.org/10.15585/mmwr.mm6529e1>.

(Box 2). Transfer to a facility with access to pediatric subspecialty care might facilitate this evaluation. However, the decision should not be based solely on the presence of maternal Zika virus infection during pregnancy. Health care providers should consider both the immediate needs of the infant and the potential negative impact of possible separation from his or her family. The recommended evaluation includes a complete

blood count and metabolic panel, including liver function tests, a comprehensive examination by an ophthalmologist, ABR testing, and consideration of advanced neuroimaging in consultation with a neurologist. In addition, infants should be evaluated for other causes of microcephaly or intracranial calcifications, including genetic conditions and other congenital infections.

Infants born to mothers with risk factors for maternal Zika virus infection (travel to or residence in an area of Zika virus transmission or sex with a partner who traveled to or resided in such an area) and for whom maternal testing was not performed before delivery, should have a comprehensive physical examination, including standardized measurement of head circumference. Maternal diagnostic testing should be performed (20,22), and testing of the placenta for Zika virus PCR should be considered (<http://www.cdc.gov/zika/hc-providers/test-specimens-at-time-of-birth.html>); infant testing should be performed if maternal testing is consistent with laboratory evidence of Zika virus infection. If an infant appears clinically well, further evaluation, including head ultrasound, ophthalmologic assessment, and infant laboratory Zika virus testing, can be deferred until maternal test results are available. However, if there is concern about infant follow-up, head

**BOX 2. Initial clinical evaluation and management of infants with laboratory evidence of Zika virus infection and abnormalities consistent with congenital Zika syndrome**

- Consultation with:
  - Neurologist for determination of appropriate neuroimaging and additional evaluation.
  - Infectious disease specialist for diagnostic evaluation of other congenital infections (e.g., syphilis, toxoplasmosis, rubella, cytomegalovirus infection, lymphocytic choriomeningitis virus infection, and herpes simplex virus infection).
  - Ophthalmologist for comprehensive eye exam and evaluation for possible cortical visual impairment prior to discharge from the hospital or within 1 month of birth.
  - Endocrinologist for evaluation for hypothalamic or pituitary dysfunction.
  - Clinical geneticist to evaluate for other causes of microcephaly or other anomalies if present.
- Consider consultation with:
  - Orthopedist, physiatrist, or physical therapist for the management of hypertonica, club foot or arthrogryptic-like conditions.
  - Pulmonologist or otolaryngologist for concerns about aspiration.
  - Lactation specialist, nutritionist, gastroenterologist, or speech or occupational therapist for the management of feeding issues.
- Perform auditory brainstem response to assess hearing.
- Perform complete blood count and metabolic panel, including liver function tests.
- Provide family and supportive services.

ultrasound, ophthalmologic assessment and infant Zika virus testing should be performed before hospital discharge. CDC recommends standard precautions in all health care settings to protect both health care personnel and patients from infection with blood-borne pathogens, including Zika virus (25).

Although Zika virus has been detected in breast milk (26), no cases of Zika virus infection associated with breastfeeding have been reported, and current evidence suggests that the benefits of breastfeeding outweigh the theoretical risks of Zika virus transmission. All women with Zika virus infection during pregnancy should be encouraged and supported to breastfeed their infants, regardless of infant Zika virus testing results.

**Outpatient Management of Infants with Laboratory Evidence of Zika Virus Infection and Abnormalities Consistent with Congenital Zika Syndrome**

The care of infants with abnormalities consistent with congenital Zika syndrome requires a multidisciplinary team and an established medical home to facilitate the coordination of care, which is critical to ensuring that these infants receive necessary testing and consultations (Box 3), and that abnormal findings are detected and appropriately addressed (27). If abnormalities are noted on prenatal evaluation, counseling specific to congenital Zika syndrome should occur during pregnancy, preferably with the involvement of obstetric and pediatric providers. Before the infant's discharge from the birth hospital, follow-up appointments with specialists and services recommended during initial evaluation should be made. Consideration should be given to using preexisting coordinated multidisciplinary care clinics.

Infants should receive routine preventive pediatric health care, including regularly scheduled immunizations (24). Families of infants with congenital Zika syndrome should receive information that includes discussion of concerns for development, function, feeding and growth, and prognosis. Standardized measurement of growth parameters, including head circumference, weight, and length, should occur regularly through the first year of life.

Breastfeeding should be encouraged and supported for nutrition and enhanced bonding. Primary care providers should assess the infant for evidence of feeding difficulties and refer for consultations related to lactation, occupational therapy, speech therapy, nutrition, and/or gastroenterology for poor suck, swallowing dysfunction, gastroesophageal reflux, and aspiration. Swallowing dysfunction might not be evident initially and feeding should be monitored closely.

A neurologic examination should be performed at age 1 month and 2 months by a primary care provider and subsequently as

**BOX 3. Outpatient management of infants with laboratory evidence of Zika virus infection and abnormalities consistent with congenital Zika syndrome**

- A medical home should be established, and visits with primary care provider should occur monthly for at least the first 6 months of life.
  - Follow growth parameters; monitor development; provide routine immunizations, anticipatory guidance, and psychosocial support; and ensure infants receive necessary testing and consultations.
- Neurologic examination by the primary care provider at 1 and 2 months of age. Refer to neurology for any abnormalities, or for any parental or provider concerns.
- Refer to developmental specialist and early intervention services.
- Repeat comprehensive ophthalmologic exam at age 3 months, and refer to ophthalmology for any abnormal findings, or for any parental or provider concerns.
- Repeat auditory brainstem response testing at age 4–6 months, and refer to audiology for any abnormal findings, or for any parental or provider concerns.
- Repeat testing for hypothyroidism at age 2 weeks and age 3 months, even if the initial testing results were normal. Refer to endocrinology for any abnormal findings.
- Provide family and supportive services.

needed depending on the infant's clinical status. If not already initiated, neurology referral should occur for evaluation of any abnormalities, including sleep problems and excess irritability. If the ophthalmology exam performed within the first month of life was normal, another exam (including retinal assessment) is recommended at age 3 months. ABR testing is the preferred test to detect hearing loss resulting from neurologic damage. If the initial newborn hearing screen was performed using only otoacoustic emission testing, the infant should be referred for ABR screening before 1 month of age. If the newborn hearing screen was normal, an ABR should be performed at age 4–6 months. If vision or hearing results are abnormal, referrals to appropriate specialists should occur as soon as possible.

Infants with abnormal brain development can be at risk for hypothalamic dysfunction leading to pituitary insufficiency, and early manifestations of endocrine dysfunction might not be detected by routine newborn screening (28). Thyroid screening, including measurement of thyroid stimulation hormone (TSH) and thyroxine (either free T<sub>4</sub> or both total T<sub>4</sub> and estimated free T<sub>4</sub>) should be performed at age 2 weeks and again at age 3 months. If either of these results is abnormal,

further evaluation of pituitary function should be performed by an endocrinologist.

Developmental monitoring should occur at each routine visit, and standardized, validated screening tools should be used to assess the presence of developmental delay (24). Referral to a developmental specialist and early intervention services should occur as soon as possible. It is important that primary care providers continue to monitor the child's development and progress with standardized, validated developmental screening tools to ensure that the child's developmental needs are addressed.

Overall, families and caregivers of infants with congenital Zika syndrome will require ongoing psychosocial assessment and support. Health care providers should work closely with parents to ensure that the care plan that is developed is consistent with the infant's needs and the family's wishes. Monitoring for depression among caregivers should occur during primary care visits, because depression or family stress might be associated with the infant's complex medical needs. Families might also face financial stressors, social stigma, and other forms of discrimination. Existing national and local resources for families of children with complex care needs should be made available to families (29).

Referrals for abnormal findings should occur as clinically indicated, either to a pediatric specialist or a specialist with expertise in the care of children. In areas with limited access to pediatric subspecialty care, the numerous services recommended for infants with congenital Zika syndrome might not be readily available; in these situations, telehealth might be explored as a potential means of providing subspecialty care and support to families in areas with limited access (30).

### **Outpatient Management of Infants with Laboratory Evidence of Zika Virus Infection but Without Abnormalities Consistent with Congenital Zika Syndrome**

Infants with laboratory evidence of Zika virus infection but without apparent abnormalities at birth are recommended to have additional monitoring (Box 4), until further information is available regarding outcomes, because some neurologic sequelae of congenital Zika virus infection (e.g., seizures, cognitive impairment, and vision and hearing abnormalities) might be subtle or have delayed onset. During routine infant follow-up with primary care providers, a standardized, validated developmental screening tool should be used at age 9 months, as currently recommended by the American Academy of Pediatrics (24), or sooner, if there are any developmental concerns. Referral to a developmental specialist and early intervention programs should be considered as soon as caregiver or provider concerns are noted, and additional referrals to specialists should be made as clinically indicated.

A vision screening, including assessment of visual regard, should be performed at each well child visit, and referral to an ophthalmologist should be made for any caregiver or provider concerns. Infants with abnormalities on initial hearing screen should be referred to an audiologist for a complete evaluation. Later development of hearing loss in infants without other clinical findings has been observed in other congenital infections (15); however, the likelihood that an infant with congenital Zika virus infection without clinical findings consistent with congenital Zika syndrome and with an initial normal hearing screen will develop hearing loss is unknown. ABR testing of infants at age 4–6 months can be considered, although the risk from sedation needs to be taken into account. Infants who passed an initial ABR and without an ABR at age 4–6 months should be referred for behavioral audiologic diagnostic testing at age 9 months, or sooner for any hearing concerns. Behavioral audiologic testing is recommended because of the potential need for sedation with ABR testing in infants.

As a critical component of patient care and to facilitate early identification of developmental delays, families should be empowered to be active participants in their child's monitoring and care. Anticipatory guidance provided to caregivers should

emphasize developmental milestones, feeding and growth, sleep, irritability, and seizure recognition.

A disproportionate burden of congenital Zika virus infection might affect families with already limited access to health care. Families might face language and cultural barriers, financial barriers, and inadequate access. Rural populations might have difficulty accessing specialists. Barriers to care for all affected infants and their families should be addressed through linkage to national, state, and local health programs.

### Contributors

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#### BOX 4. Outpatient management of infants with laboratory evidence of Zika virus infection, but without abnormalities consistent with congenital Zika syndrome

- A medical home should be established.
  - Follow growth parameters, and perform developmental screening at each well child visit.
  - Emphasize anticipatory guidance for families regarding developmental milestones, feeding and growth, sleep and irritability, and abnormal movements.
- Use a standardized, validated developmental screening tool at 9 months as currently recommended, or earlier for any parental or provider concerns.
- Referral to ophthalmology for comprehensive eye exam within one month of birth. Perform vision screening and assess visual regard at every well child visit, and refer to ophthalmology for any abnormal findings, or for any parental or provider concerns.
- Perform auditory brainstem response within one month of birth. Consider repeat auditory brainstem response at age 4–6 months or perform behavioral diagnostic testing at age 9 months and refer to audiology for any abnormal findings, or for any parental or provider concerns.
- Provide family and supportive services.

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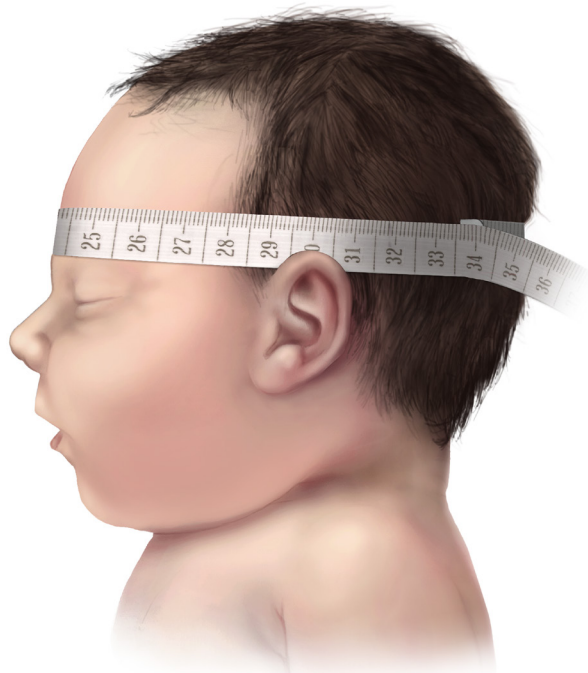
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# MEASURING HEAD CIRCUMFERENCE



Typical Head Size

Typical Head Size



**Baby with Typical Head Size**



**Baby with Microcephaly**



**Baby with Severe Microcephaly**

- Use a measuring tape that cannot be stretched
- Securely wrap the tape around the widest possible circumference of the head
  - » Broadest part of the forehead above eyebrow
  - » Above the ears
  - » Most prominent part of the back of the head

- Take the measurement three times and select the largest measurement to the nearest 0.1 cm
- Head circumference measurements should be taken on the first day of life because commonly-used birth head circumference reference charts by age and sex are based on measurements taken before 24 hours of age

For more information: [www.cdc.gov/zika](http://www.cdc.gov/zika)



U.S. Department of  
Health and Human Services  
Centers for Disease  
Control and Prevention

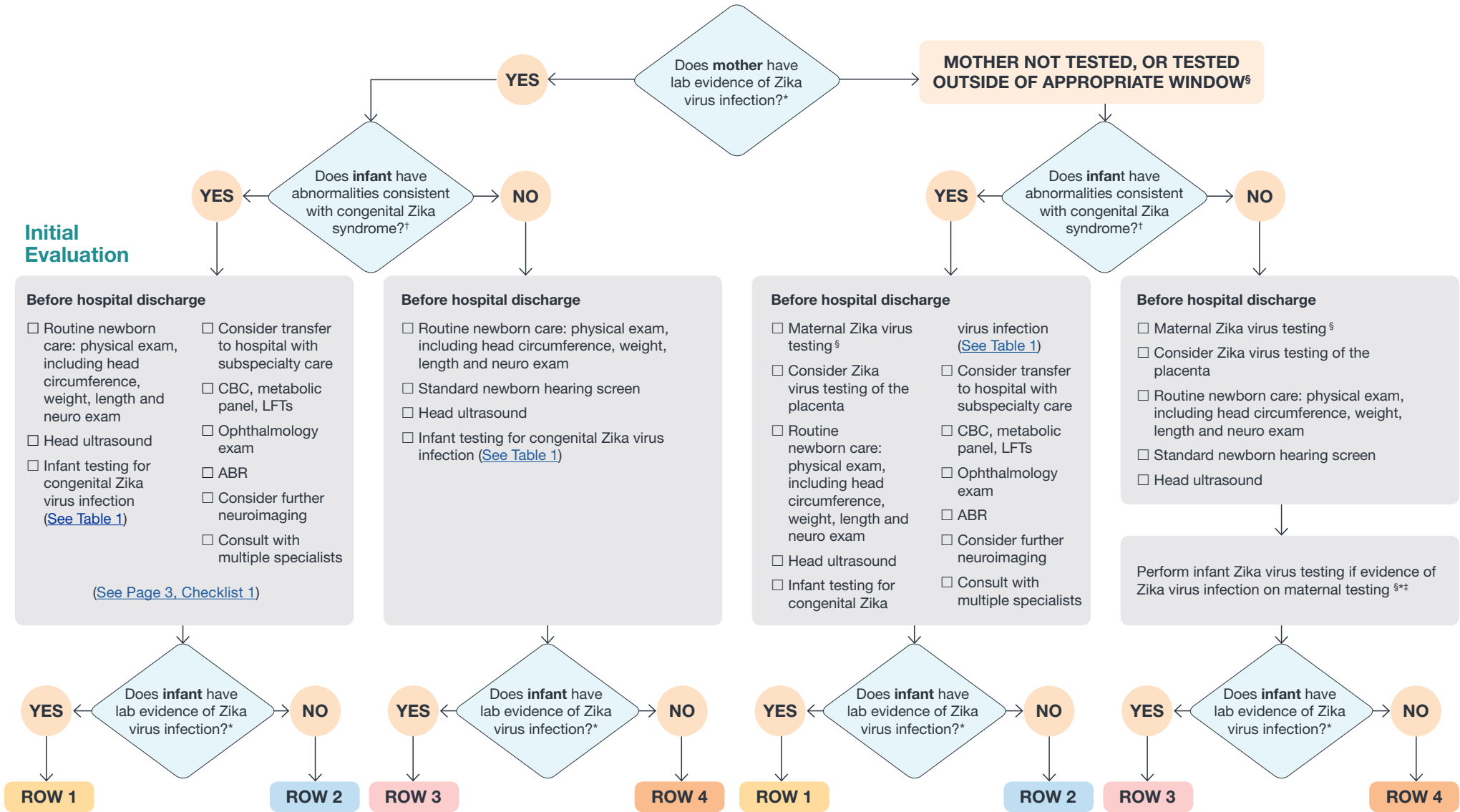


## DIAGNOSIS



# INITIAL EVALUATION AND OUTPATIENT MANAGEMENT DURING THE FIRST 12 MONTHS OF LIFE FOR INFANTS WITH POSSIBLE CONGENITAL ZIKA VIRUS INFECTION

## Initial Evaluation



Follow management and follow-up recommendations indicated in Outpatient Management Checklist

**Outpatient Management Checklist\*\***

|   | 2 weeks   | 1 month                             | 2 months                            | 3 months  | 4-6 months   | 9 months   | 12 months |
|---|---|-------------------------------------|-------------------------------------|---|--|--|-----------|
| <b>ROW 1</b><br>Infant with abnormalities consistent with congenital Zika syndrome† and laboratory evidence of Zika virus infection*    | <input type="checkbox"/> Thyroid screen (TSH & T4)  | <input type="checkbox"/> Neuro exam | <input type="checkbox"/> Neuro exam | <input type="checkbox"/> Thyroid screen (TSH & T4)<br><input type="checkbox"/> Ophthalmology exam | <input type="checkbox"/> Repeat audiology evaluation (ABR) |  |           |
|   | <input type="checkbox"/> Routine preventive health care including monitoring of feeding and growth<br><input type="checkbox"/> Routine and congenital infection-specific anticipatory guidance<br><input type="checkbox"/> Referral to specialists, including evaluation of other causes of congenital anomalies as needed<br><input type="checkbox"/> Referral to early intervention services<br>(See Page 3, Checklist 2) |                                     |                                     |   |  |  |           |
| <b>ROW 2</b><br>Infant with abnormalities consistent with congenital Zika syndrome† and negative for Zika virus infection               | <input type="checkbox"/> Continue to evaluate for other causes of congenital anomalies<br><input type="checkbox"/> Further management as clinically indicated   |                                     |                                     |   |  |  |           |
| <b>ROW 3</b><br>Infant with no abnormalities consistent with congenital Zika syndrome† and laboratory evidence of Zika virus infection* | <input type="checkbox"/> Ophthalmology exam<br><input type="checkbox"/> ABR   |                                     |                                     |   | <input type="checkbox"/> Consider repeat ABR               | <input type="checkbox"/> Behavioral audiology evaluation if ABR not done at 4-6 months |           |
|   | <input type="checkbox"/> Monitoring of growth parameters (HC, weight, and height), developmental monitoring by caregivers and health care providers, and age-appropriate developmental screening at well-child visits (See Page 3, Checklist 3)   |                                     |                                     |   |  |  |           |
| <b>ROW 4</b><br>Infant with no abnormalities consistent with congenital Zika syndrome† and negative for Zika virus infection            | <input type="checkbox"/> Monitoring of growth parameters (HC, weight, and height), developmental monitoring by caregivers and health care providers, and age-appropriate developmental screening at well-child visits   |                                     |                                     |   |  |  |           |

**Abbreviations:** rRT-PCR = real-time reverse transcription–polymerase chain reaction; IgM = immunoglobulin M; CBC = complete blood count; LFTs = liver function tests, PE = physical examination; US = ultrasound; ABR = auditory brainstem response; CT = computed tomography; MRI = magnetic resonance imaging; neuro = neurologic; HC = Head (occipitofrontal) circumference

\* Laboratory evidence of Zika virus infection includes: (1) Zika virus RNA detected by real-time reverse transcription-polymerase chain reaction (rRT-PCR) in any clinical specimen; or (2) positive Zika virus IgM. Confirmatory neutralizing antibody titers are needed in addition to IgM for maternal Zika virus infection. Cord blood and testing of the placenta not recommended for infant testing for Zika virus.

\*\* Outpatient management checklist for infants born to a woman with laboratory evidence of confirmed or possible Zika virus infection.

† Findings consistent with congenital Zika virus syndrome can include microcephaly, intracranial calcifications, or other brain or eye abnormalities.

§ Mothers who travelled to or reside in an area of active Zika transmission or who had unprotected sex with a partner who had traveled to or resided in an area with active transmission should be tested by rRT-PCR within 2 weeks of exposure or symptom onset, or IgM within 2-12 weeks of exposure or symptom onset. Because of the decline in IgM antibody and viral RNA levels over time, negative maternal testing 12 weeks after exposure or symptom onset does not rule out maternal infection.

‡ Infant testing is recommended within the first two days after birth; if testing is performed later, it can be difficult to distinguish congenital infection from perinatally or postnatally acquired infection.

TABLE 1

**Interpretation of results of laboratory testing of infant's blood, urine and/or cerebrospinal fluid for evidence of congenital Zika virus infection**

| Infant test results* |                      | Interpretation  |
|----------------------|----------------------|---|
| <b>rRT-PCR</b>       | <b>IgM</b>           |   |
| Positive             | Positive or Negative | Confirmed congenital Zika virus infection                 |
| Negative             | Positive             | Probable congenital Zika virus infection <sup>+</sup>     |
| Negative             | Negative             | Negative for congenital Zika virus infection <sup>+</sup> |

**Abbreviations:** rRT-PCR = real-time reverse transcription-polymerase chain reaction; IgM = Immunoglobulin M

\* Infant serum, urine or cerebrospinal fluid.

+ Laboratory results should be interpreted in the context of timing of infection during pregnancy, maternal serology results, clinical findings consistent with congenital Zika syndrome, and any confirmatory testing with plaque reduction neutralization testing (PRNT).

**CHECKLIST 1**

**Initial clinical evaluation & management of infants with laboratory evidence of Zika virus infection and abnormalities consistent with congenital Zika syndrome <sup>†</sup>**

**Consultation with:**

- Neurologist for determination of appropriate neuroimaging and additional evaluation.
- Infectious disease specialist for diagnostic evaluation of other congenital infections (e.g. syphilis, toxoplasmosis, rubella, cytomegalovirus infection, lymphocytic choriomeningitis virus infection, and herpes simplex virus infection).
- Ophthalmologist for comprehensive eye exam and evaluation for possible cortical visual impairment prior to discharge from hospital or within 1 month of birth.
- Endocrinologist for evaluation for hypothalamic or pituitary dysfunction.
- Clinical geneticist to evaluate for other causes of microcephaly or other anomalies if present.

**Consider consultation with:**

- Orthopedist, physiatrist and physical therapist for the management of hypertonia, club foot or arthrogrypotic-like conditions.
- Pulmonologist or otolaryngologist for concerns about aspiration.
- Lactation specialist, nutritionist, gastroenterologist, or speech or occupational therapist for the management of feeding issues.
- Perform ABR to assess hearing.
- Perform complete blood count and metabolic panel, including liver function tests.
- Provide family and supportive services.

**CHECKLIST 2**

**Outpatient management of infants with laboratory evidence of Zika virus infection and abnormalities consistent with congenital Zika syndrome <sup>†</sup>**

- A medical home should be established, and visits with primary care provider should occur monthly for at least the first 6 months of life.
  - Follow growth parameters, monitor development, encourage parents and other caregivers to monitor child's development, provide routine immunizations and anticipatory guidance, psychosocial support, and to ensure infants receive necessary testing and consultations.
- Neurologic examination by the primary care provider at 1 and 2 months of age. Refer to neurology for any abnormalities, or for any parental or provider concerns.
- Refer to developmental specialist and early intervention services.
- Repeat a comprehensive ophthalmologic exam at 3 months of age, and refer to ophthalmology for any abnormal findings, or for any parental or provider concerns.
- Repeat ABR testing at 4-6 months of age, and follow up on any abnormal findings, or for any parental or provider concerns.
- Repeat testing for hypothyroidism (i.e. TSH, total T4 and estimated free T4) at 2 weeks and 3 months of age, even if the initial testing was normal. Refer to endocrinology for any abnormal findings.
- Provide family and supportive services.

**CHECKLIST 3**

**Outpatient management of infants with laboratory evidence of Zika virus infection, but without abnormalities consistent with congenital Zika syndrome <sup>†</sup>**

- A medical home should be established.
  - Follow growth parameters, perform developmental monitoring at each well child visit and encourage parents and other caregivers to monitor child's development.
- Emphasize anticipatory guidance for families regarding developmental milestones, feeding and growth, sleep and irritability, and abnormal movements.
- Use a standardized, validated developmental screening tool at 9 months as currently recommended, or earlier for any parental or provider concerns.
- Referral to ophthalmology for comprehensive eye exam within one month of birth. Perform vision screening and assess visual regard at every well child visit, and refer to ophthalmology for any abnormal findings, or for any parental or provider concerns.
- Perform ABR within one month of birth. Perform behavioral diagnostic testing at 9 months of age, or consider repeat ABR at 4-6 months. Refer to audiology for any abnormal findings, or for any parental or provider concerns.
- Provide family and supportive services.

# ZIKA VIRUS: COLLECTION AND SUBMISSION OF SPECIMENS FOR ZIKA VIRUS TESTING AT TIME OF BIRTH



## General Information

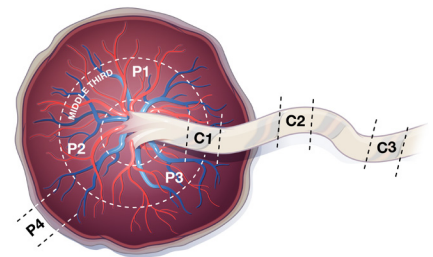
Laboratory testing for congenital Zika virus infection is recommended for infants born to mothers with laboratory evidence of Zika virus infection during pregnancy, and for infants who have abnormal clinical findings suggestive of congenital Zika virus syndrome and a maternal epidemiologic link suggesting possible transmission, regardless of maternal Zika virus test results.

For infants born to mothers with risk factors for maternal Zika virus infection (travel to or residence in an area of Zika virus transmission or sex with a partner with travel to or residence in such an area) for whom maternal testing was not performed before delivery, assessment of the infant, including comprehensive physical exam and careful measurement of head circumference should be performed. Maternal diagnostic testing should be performed and testing of the placenta for Zika virus PCR should be considered. If an infant appears clinically well, further evaluation and infant testing can be deferred until maternal test results are available. However, if there is concern about infant follow-up, infant testing should be performed before hospital discharge.

**IMPORTANT: Pre-approval is *required* prior to submission of any placental or other tissue specimens. For pre-approval please contact [pathology@cdc.gov](mailto:pathology@cdc.gov) and [eocevent189@cdc.gov](mailto:eocevent189@cdc.gov).**

### Healthcare Providers:

- Please contact your state, tribal, local, or territorial health department to facilitate laboratory testing and pathology specimen submission.
  - » If available in your hospital/institution, please consult surgical pathology to ensure appropriate collection and processing of tissue specimens for Zika virus testing.
  - » Please see table below for information on collection of specimens for Zika virus testing.
- **Specimens should ONLY be sent to CDC directly from health departments.** CDC's Zika Pregnancy Hotline (770-488-7100; or email [zikapregnancy@cdc.gov](mailto:zikapregnancy@cdc.gov)) is available 24/7 to healthcare providers and health departments for consultation regarding management of pregnant women and infants with possible Zika virus. This hotline can also assist with questions regarding specimen submission.



**Figure:** Collecting placental specimen

### Health Departments:

- When submitting specimens, please submit [CDC Form 50.34](#) with all specimens. For test order name, write "Zika virus".
- **Pre-approval is required** prior to submission of all tissue specimens (i.e., placenta, umbilical cord). Please contact [pathology@cdc.gov](mailto:pathology@cdc.gov) and [eocevent189@cdc.gov](mailto:eocevent189@cdc.gov) to discuss the case and obtain pre-approval. If you have additional questions for the Infectious Diseases Pathology Branch, please call 404-639-3133.
- If you have additional questions for the Arboviral Diseases Branch, please call 970-221-6400.

### Reporting of Results:

- Test results will be reported to the state health department and the submitting healthcare provider. Results will not be directly released to patients.
- Turnaround time will depend on testing volume and established reporting systems.



**U.S. Department of Health and Human Services**  
Centers for Disease Control and Prevention

| Specimen Type                              | General Instructions   | Notes  | Storage   | Shipping   |
|--|--|--|---|--|
| <p><b>Infant serum</b></p>                 | <p>At least 1.0 ml</p> <p>Transfer serum to a plastic tube measuring approximately 50 mm tall and 15 mm in diameter (e.g., 1.8 mL cryotube or 2.0 mL microtube) with screw cap and secure with thermoplastic, self-sealing lab film.</p>   | <p>For antibody and rRT-PCR testing, specimens should be kept cold (2–6 °C) or frozen (-70 °C).</p> <p>For virus isolation testing, specimens should be frozen as soon as possible (-70 °C).</p> | <p>For cold specimens, the sample should be placed in an insulated container with adequate ice packs to ensure specimen (“cold chain”) integrity.</p> <p>For frozen specimens, ship the sample on enough dry ice to ensure specimens remain frozen until received.</p>                                    | <p>Arboviral Diseases Branch<br/>Diagnostic Laboratory<br/>Centers for Disease Control and Prevention<br/>3156 Rampart Road<br/>Fort Collins, Colorado<br/>80521</p> <p>More information about collecting, handling, and shipping is available <a href="#">here</a>.</p> |
| <p><b>Placenta and fetal membranes</b></p> | <p>Several full thickness pieces including at least 3 full thickness pieces (0.5–1 cm x 3–4 cm in depth) from middle third of placental disk and at least 1 from the placental disk margin</p> <p>5 x 12 cm strip of fetal membranes</p> <p>Please include sections of the placental disk, fetal membranes, and pathologic lesions when possible.</p> <p><i>(Please reference the figure on page one.)</i></p> | <p>Please include information about placenta weight and sample both maternal and fetal side of the placenta.</p> <p>Label all specimens to identify location of sample.</p>                      | <p>Fix specimens in formalin</p> <p>Volume of formalin used should be about 10x mass of tissue. Place in 10% neutral buffered formalin for a minimum of 3 days. Once fully fixed the tissue can be transferred to 70% ethanol for long term storage.</p> <p>Storage and shipping at room temperature.</p> | <p>Infectious Diseases Pathology Branch<br/>Centers for Disease Control and Prevention<br/>1600 Clifton Rd. NE, MS G-32<br/>Atlanta GA 30329-4027</p> <p>More instructions can be found <a href="#">here</a>.</p>  |
| <p><b>Umbilical cord</b></p>               | <p>2.5 cm segments of cord</p> <p>4 or more specimens</p>  | <p>Umbilical cord segments should be obtained proximal, middle, and distal to umbilical cord insertion site on the placenta.</p> <p>Label all specimens to identify location of sample.</p>      | <p>Fix specimens in formalin</p> <p>Volume of formalin used should be about 10x mass of tissue. Place in 10% neutral buffered formalin for a minimum of 3 days. Once fully fixed the tissue can be transferred to 70% ethanol for long term storage.</p> <p>Storage and shipping at room temperature.</p> | <p>Infectious Diseases Pathology Branch<br/>Centers for Disease Control and Prevention<br/>1600 Clifton Rd. NE, MS G-32<br/>Atlanta GA 30329-4027</p> <p>More instructions can be found <a href="#">here</a>.</p>  |
| <p><b>Infant urine</b></p>                 | <p>Provide 0.5–1.0 mL of the specimen in a sterile screw capped vial secured with a small piece of thermoplastic, self-sealing lab film. Please ensure a tight seal as leaking specimens cannot be accepted.</p>   | <p>Sterile specimen is not required</p>  | <p>For rRT-PCR testing, specimens should be kept cold (2–8 °C) or frozen (-≤ 20 °C) for storage and shipping.</p> <p>For frozen specimens, ship the sample on enough dry ice to ensure specimens remain frozen until received.</p>  | <p>Arboviral Diseases Branch<br/>Diagnostic Laboratory<br/>Centers for Disease Control and Prevention<br/>3156 Rampart Road<br/>Fort Collins, Colorado<br/>80521</p> <p>Get more information about <a href="#">collecting, handling, and shipping</a>.</p>               |

# ZIKA VIRUS: COLLECTION AND SUBMISSION OF FETAL TISSUES FOR ZIKA VIRUS TESTING



## General Information

The following information applies to fetal tissue collection and submission. For cord blood and amniotic fluid analysis, please see [CDC's web page on testing body fluid specimens](#).

**IMPORTANT: Pre-approval is required prior to submission of any tissue specimens. For pre-approval please contact [pathology@cdc.gov](mailto:pathology@cdc.gov) and [eocevent189@cdc.gov](mailto:eocevent189@cdc.gov).**

- **Healthcare Providers:** Please make sure that your state, territorial, tribal, or local health department has been notified and has received pre-approval from CDC for submission and shipment of specimens before they are collected and sent.
  - » **Institutions with surgical pathology available:** Please consult surgical pathology regarding appropriate collection and processing of specimens for Zika virus testing.
  - » **Institutions without surgical pathology available:** Please see table below for general guide on collection of tissue specimens for Zika virus testing.
  - » **Specimens should ONLY be sent to CDC from health departments.**
- **Health Departments:** Pre-approval is required prior to the submission of specimens to CDC. Information required for the pre-approval process includes:
  - » Maternal/neonatal state and specimen identification numbers, maternal age, Zika virus test results, travel locations and dates, illness onset (if applicable), estimated date of delivery, gestational age at delivery, pregnancy outcome, age and sex of infant, birth anthropometric measurements, any additional testing/imaging.
  - » Please specify cases that have been reported to the US Zika Pregnancy Registry and for which this information has already been provided during the pre-approval process.
- **Please Note:** [CDC Form 50.34](#) is required to be submitted with all specimens. Please write "Zika virus" in test order name after it is printed as this is not yet an option on the drop down menu.
  - » Select Test Order CDC-10371 for infant deaths (pathologic evaluation of infant death due to infection)
  - » Select Test Order CDC-10372 for pregnancy losses (pathologic evaluation of illness due to infection)

## Collection of Fetal or Neonatal Tissues

- Appropriate consent from the parents or guardian must be obtained by the healthcare provider prior to collection and submission of specimens for Zika virus testing.
- To optimize evaluation of possible Zika virus infection in fetal tissues, send fixed tissues. Submission of frozen tissues may be considered on a case by case basis, please email [pathology@cdc.gov](mailto:pathology@cdc.gov) and [ZIKA\\_EPI\\_ADB@cdc.gov](mailto:ZIKA_EPI_ADB@cdc.gov) for consultation.



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- The type of tissues available for evaluation will depend on the gestational age of the fetus and the collection procedure that is performed. Effort should be made to maintain the tissue architecture, and to minimize any dissection or disruption of the tissues.
- For situations in which individual organs or tissue types cannot be identified, please provide any available tissue with minimal disruption.
- CDC Infectious Diseases Pathology Branch (IDPB) accepts microscopic or gross photos from health departments as part of either teleradiology consultation or routine tissue specimen submission for diagnostic evaluation. Photos should not contain patient names or medical record numbers. Visit the CDC ePathology teleradiology (<http://www.cdc.gov/ncezid/dhcpp/idpb/epathology/index.html>) page for more details.
- Staff who collect and handle specimens should refer to Zika biosafety guidelines for laboratory and pathology procedures [www.cdc.gov/zika/state-labs/biosafety-guidance.html](http://www.cdc.gov/zika/state-labs/biosafety-guidance.html).

| Specimen Type  | Fixed Specimens   | When to Consider                              | General Notes  |
|--|---|---|--|
| <b>Products of conception (POC)</b>  | <ul style="list-style-type: none"> <li>• 4 or more specimens</li> </ul>   | Generally less than 12wks gestational age     | For early pregnancy loss/ miscarriage, please send POCs fixed in formalin.   |
| <b>Placenta and fetal membranes</b>  | <ul style="list-style-type: none"> <li>• Several full thickness pieces including at least 3 full thickness pieces (0.5–1 cm x 3–4 cm in depth) from middle third of placental disk and at least 1 from the placental disk margin</li> <li>• One 5 x 12 cm strip of fetal membranes</li> </ul> | Any gestation for which placenta is available | <p>Please include sections of the placental disk, fetal membranes, and pathologic lesions when possible.</p> <p>Please include information about placenta weight and sample both maternal and fetal side of the placenta.</p> <p>Label all specimens to identify location of sample.</p> |
| <b>Umbilical cord</b>  | <ul style="list-style-type: none"> <li>• 2.5 cm segments of cord</li> <li>• 4 or more specimens</li> </ul>  | Any gestation for which placenta is available | <p>Umbilical cord segments should be obtained proximal, middle, and distal to umbilical cord insertion site on the placenta.</p> <p>Label all specimens to identify location of sample.</p>  |
| <b>Brain and spinal cord</b>   | <ul style="list-style-type: none"> <li>• 0.5–1.0 cm<sup>3</sup> each</li> <li>• 5 or more specimens from different parts of brain and spinal cord</li> </ul>  | Fetal demise                                  | It is critical to maintain the tissue architecture to evaluate viral pathology. Certain fetal tissues require longer fixation, please fix brain specimens for 48-72 hours.   |
| <b>Solid organ (heart, lung, liver, kidneys, skeletal muscle, eyes, bone marrow)</b> | <ul style="list-style-type: none"> <li>• 0.5-1.0 cm<sup>3</sup> each</li> <li>• 1 representative specimen from each solid organ</li> </ul>  | Fetal demise                                  | Submission of eyes is highly recommended.  |



## Fixed Tissues

- Histopathology, immunohistochemical staining, and reverse transcription-polymerase chain reaction (RT-PCR) will be performed on fixed tissues, as needed. Fixed tissues may include formalin fixed and/or paraffin embedded tissues.
- The volume of formalin used to fix tissues should be 10x the volume of tissue. Place tissue in 10% buffered formalin for a minimum of three days or until fully fixed. After fixation, tissue can be transferred to 70% ethanol for long term storage.
- If stored prior to shipping, please transfer fixed tissues to 70% ethanol after 72 hours.
- Fixed tissues should be stored and shipped at room temperature. Additional instructions for [collecting, handling, and shipping](#) formalin-fixed tissues are also available. Paraffin blocks should be submitted in accordance with these instructions for formalin-fixed specimens.
- DO NOT FREEZE samples that have been fixed in formalin.

## Submission and Shipping of Specimens

- [\[CDC Form 50.34\]](#) is required with all specimen submissions and specimens should ONLY be sent to CDC directly from health departments. Please see introduction above for further details.
- Fixed specimens can be shipped at ambient temperature to:  
Infectious Diseases Pathology Branch  
Centers for Disease Control and Prevention  
1600 Clifton Rd. NE, MS G-32  
Atlanta GA 30329-4027
- More information on shipping can be found here: <http://www.cdc.gov/ncezid/dhcpp/idpb/specimen-submission/cns.html>.

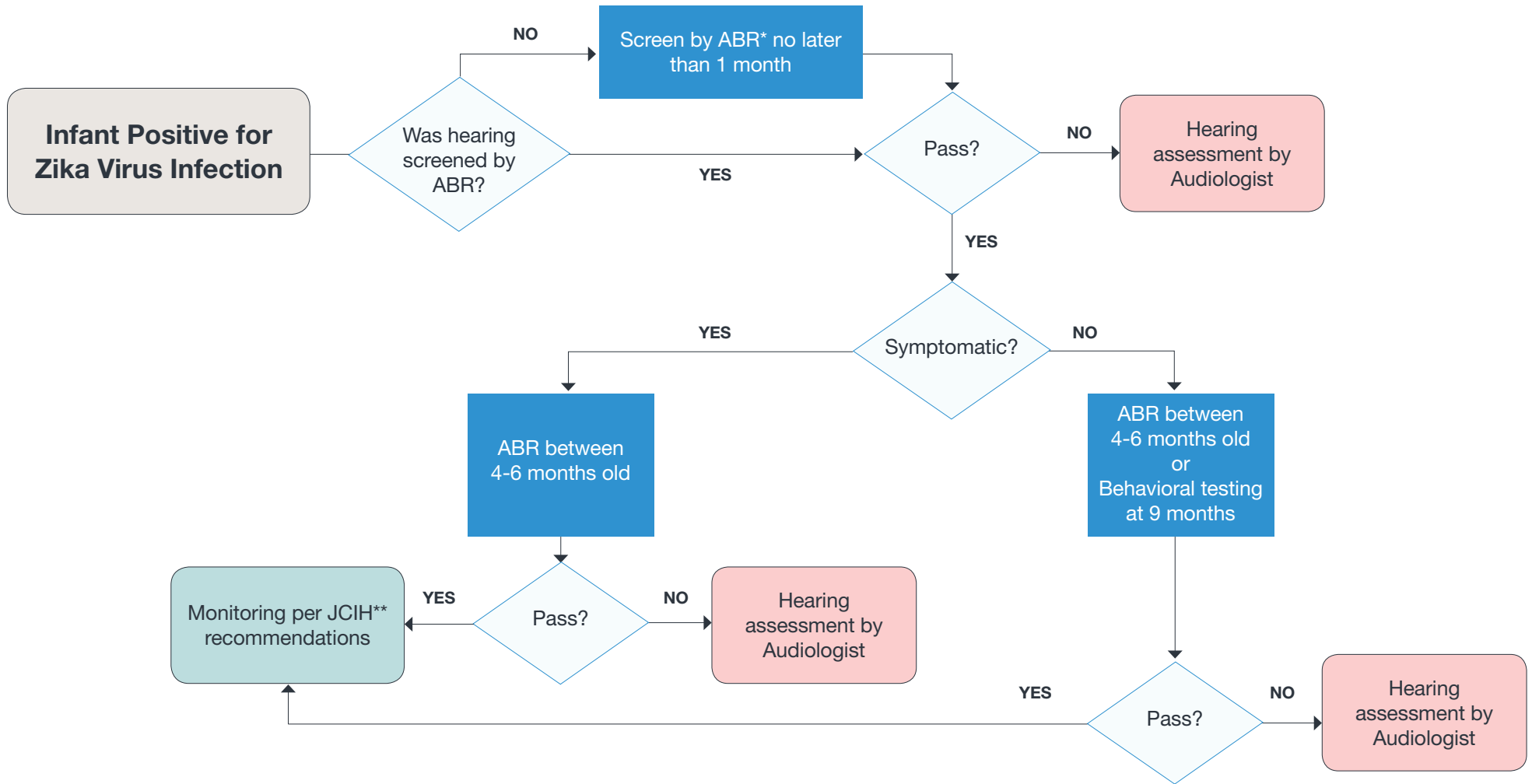
## Reporting of Results

- Test results will be reported to the state health department and the submitting healthcare provider.
- Turnaround time will vary, depending on testing volume.
- Considerations for interpreting pathology results include maternal/infant epidemiologic risk factors, maternal/infant Zika testing results, and clinical presentation. For assistance with interpretation of pathology reports results please contact [pathology@cdc.gov](mailto:pathology@cdc.gov).

# ASSESSMENT OF **INFANT HEARING**



## For Infants Testing Positive for Zika Virus Infection



\***ABR** - Auditory Brainstem Response    \*\***JCIH** - Joint Committee on Infant Hearing



# WHAT TO KNOW IF YOUR BABY WAS BORN WITH CONGENITAL ZIKA SYNDROME



As a parent of a new baby with health conditions related to Zika infection during pregnancy, you may feel overwhelmed, worried, and unsure of how to care for your new baby. Read on to learn more about health conditions related to Zika and find out where you can go for help.

## How Might Zika Affect My Baby?

Zika infection during pregnancy can lead to a pattern of conditions, called congenital Zika syndrome, in the baby. A baby with congenital Zika syndrome, might have one or more of the conditions in the blue box.

- Smaller than expected head size, called microcephaly
- Problems with brain development
- Feeding problems, such as difficulty swallowing
- Hearing loss
- Seizures
- Vision problems
- A problem with joint movement, called contractures
- Too much muscle tone restricting body movement soon after birth

We are still learning about the effects of Zika infection during pregnancy. Babies affected by Zika may have lasting special needs. Some of the conditions listed in the blue box can lead to problems with a child's progress in moving, learning, speaking and playing, called "developmental delay." Babies with congenital Zika syndrome may experience different outcomes as they develop, but it's difficult to know how each baby will be affected. These answers may only come with more time. It is important for you to work with your doctors to manage your baby's medical care together.

## How Can I Support My Baby?

Babies with congenital Zika syndrome need support. One type of support involves getting your baby help as soon as possible for learning and developing skills, like feeding, sitting, or crawling. This type of help is called "early intervention services," and is available in the first 3 years of life. Other developmental support may be needed for any ongoing special needs. Another type of support is treatment of the conditions your baby may experience, like medication to help treat seizures.

**To help your baby get the early support and services he or she might need:**

- **Work with your doctor to create a coordinated care plan.**
    - » Work with your doctor to organize the care your baby might need. Additional testing, like hearing and vision testing, may be needed even if the first tests were normal.
  - **Keep regular appointments.**
    - » Take your baby for all recommended check-ups with his or her regular doctor, nurse, or other healthcare provider or recommended specialists. This is important for your baby's doctor or other healthcare providers to monitor your baby's development.
  - **Share your concerns.**
    - » If you have new concerns about your baby's development at any time, talk with your baby's doctor, nurse, early intervention provider, or healthcare provider. Don't wait. Acting early could make a real difference.
  - **Contact early intervention services in your community.**
    - » Reach out to your state or territory's early intervention program. Your baby may be eligible for free or low cost services. Find contact information at [www.cdc.gov/FindEI](http://www.cdc.gov/FindEI).
- You do not need a doctor's referral or a medical diagnosis to have your baby evaluated for services.**



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Control and Prevention

## Where to Find Resources and Support

**Raising a child with congenital Zika syndrome can be challenging. Thankfully, help is available for you and your baby.**

The resources below can help you find more information about Zika, locate services that might help your baby, and connect with other families.



**FIND** more information through:

- Your baby's regular doctor or a specialist whom your doctor recommends
- **CDC Zika Virus Website** | [www.cdc.gov/zika](http://www.cdc.gov/zika)
- Non-profit organizations
  - » **American Academy of Pediatrics** | Visit website: [www.healthychildren.org](http://www.healthychildren.org)  
This organization is comprised of pediatricians committed to the health of infants, children, adolescents, and young adults.
  - » **March of Dimes:** [www.marchofdimes.org](http://www.marchofdimes.org) | Ask questions: [www.marchofdimes.org/ask-us.aspx](http://www.marchofdimes.org/ask-us.aspx)  
The March of Dimes is dedicated to improving the health of babies by preventing birth defects, premature birth, and infant mortality.
  - » **The Parent Training and Information Center** in your state: [www.parentcenterhub.org/find-your-center](http://www.parentcenterhub.org/find-your-center)  
These centers provide information and training on early intervention and special education services to families of children with disabilities.



**ACCESS** regular pediatric, other health care, and early intervention services through:

- Your baby's regular doctor
- A specialist whom your doctor recommends. Babies with microcephaly might benefit from seeing other healthcare providers who specialize in certain types of care, like treating conditions of the nervous system, eye problems, or child development.
  - » State/local programs, such as early intervention and medical services for children with special healthcare needs. Call your state contact to get a free evaluation: [www.cdc.gov/FindEI](http://www.cdc.gov/FindEI)



**GET** peer support from families of children with microcephaly or other special healthcare needs through:

- Non-profit organizations
  - » **The Family Voices** affiliate or **Family-to-Family Health Information Center** in your state: [www.familyvoices.org/states](http://www.familyvoices.org/states)
  - » **Parent to Parent-USA** | Visit website: [www.p2pusa.org](http://www.p2pusa.org)
  - » **Partnerships for Parents** | Visit website: [partnershipforparents.net/](http://partnershipforparents.net/)
- Your hospital social worker. Try talking to someone about how you're feeling, be it friend or professional. Hospitals often have a social worker who can counsel you initially and connect you with additional therapeutic resources. Get the support you need to take care of yourself and your baby.

Links to organizations outside of CDC are included for information only and do not indicate any form of endorsement or approval from CDC.

**For a more complete list of resources for families, please visit**

[www.cdc.gov/zika/parents/families-of-newborns-affected-zika.html](http://www.cdc.gov/zika/parents/families-of-newborns-affected-zika.html)

[www.cdc.gov/zika](http://www.cdc.gov/zika)

## **WHAT TO KNOW** IF YOUR BABY MAY HAVE BEEN AFFECTED BY ZIKA BUT HAS NO RELATED HEALTH CONDITIONS AT BIRTH



As a parent of a new baby who may have been affected by Zika virus during pregnancy, you and your family may be worried and unsure of next steps in caring for your baby. Read on to learn more about the importance of tracking your baby's development and learn where you can go for help.

### **How Will Zika Virus Affect My Baby?**

- Zika virus infection during pregnancy can cause microcephaly and other severe brain defects in babies, but not every pregnant woman infected with Zika will have a baby with a related health condition at birth.
- While we've learned a lot about Zika in a short time, many questions remain.
- We don't yet know all of the ways Zika virus infection during pregnancy might affect a baby, including problems that may not be obvious when a baby is born.
- We also don't know how often a baby will have problems linked to Zika if a woman is infected during pregnancy.
- Children affected by Zika may have lasting special needs. Acting early to get services could make a difference.

### **What Should I Do After My Baby is Born?**

- **Work with your baby's doctor.**
  - » Because we are still learning about the longer term effects of Zika virus infection during pregnancy, it is important for you to work with your baby's doctors to manage his or her medical care.
- **Track your baby's development.**
  - » It's important to track your baby's development as he or she grows. Tracking development helps you know what your baby should be doing at certain ages and what to expect next. This will help you and your doctors identify any problems early and get your baby any needed services or support as soon as possible.

### **How Can I Best Support My Baby?**

To help your baby get the early support and services that might be needed:

- **Keep regular appointments.**
  - » Take your baby for all recommended check-ups with their regular doctor or recommended specialists.
- **Track your baby's development.**
  - » Between check-ups, track your baby's development using developmental milestone checklists from CDC ([www.cdc.gov/Milestones](http://www.cdc.gov/Milestones)).
- **Share your concerns.**
  - » If you have concerns about your baby's development at any time, talk with your child's doctor, nurse, early intervention provider, or other healthcare provider. Don't wait. Acting early can make a real difference.
- **Contact early intervention services in your community.**
  - » Reach out to your state or territory's early intervention program to find out if your baby can get free or low cost services. Find contact information at [www.cdc.gov/FindEI](http://www.cdc.gov/FindEI). **You do not need a doctor's referral or a medical diagnosis to have your baby evaluated for services.**



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## Where to Find Resources and Support

As a new parent of a baby who may have been affected by Zika virus during pregnancy, you and your family may be worried and unsure of next steps in caring for your baby. Thankfully, help is available.

The resources below can help you find more information about Zika, track your baby's development, and connect with other families for support.



**FIND** more information through:

- Your baby's regular doctor or a specialist whom your doctor recommends
- **Early Intervention Services**  
[www.cdc.gov/ncbddd/actearly/parents/states.html](http://www.cdc.gov/ncbddd/actearly/parents/states.html)
- **CDC Zika Virus Website** | [www.cdc.gov/zika](http://www.cdc.gov/zika)
- Non-profit organizations
  - » **American Academy of Pediatrics**  
Visit website: [www.healthychildren.org](http://www.healthychildren.org)
  - » **March of Dimes** | [www.marchofdimes.org](http://www.marchofdimes.org)  
Ask questions:  
[www.marchofdimes.org/ask-us.aspx](http://www.marchofdimes.org/ask-us.aspx)
  - » **The Parent Training and Information Center** in your state:  
[www.parentcenterhub.org/find-your-center](http://www.parentcenterhub.org/find-your-center)



**ACCESS** regular pediatric and other health care through:

- Your baby's regular doctor
  - » The American Academy of Pediatrics recommends that babies and children be screened for general development using standardized, validated tools at 9, 18, and 24 or 30 months or whenever a parent or provider has a concern. Ask your baby's doctor about your baby's developmental screening.
- A specialist who your doctor recommends. Babies affected by Zika during pregnancy might benefit from seeing other healthcare providers who specialize in certain types of care, like eye problems, or child development.



**TRACK** your baby's development through:

- CDC's "Learn the Signs. Act Early." program. CDC offers free tools and resources to help parents and other caregivers keep track of their child's development and get help if they are concerned.
  - » Order a free Parent Kit:  
[www.cdc.gov/ActEarly/Orders](http://www.cdc.gov/ActEarly/Orders)
  - » See photos and videos of developmental milestones to help understand what most babies and children do by different ages:  
[www.cdc.gov/MilestonesInAction](http://www.cdc.gov/MilestonesInAction)
  - » Download fact sheets on how to get help for your baby if you have concerns:  
[www.cdc.gov/Concerned](http://www.cdc.gov/Concerned)
- The "Birth to Five: Watch Me Thrive" website: [www.hhs.gov/WatchMeThrive](http://www.hhs.gov/WatchMeThrive). This site has developmental screening resources for families, including a Developmental Screening Passport.



**GET** peer support from families of children with special healthcare needs through:

- Non-profit organizations
  - » **The Family Voices** affiliate or **Family-to-Family Health Information Center** in your state | Visit website: [www.familyvoices.org/states](http://www.familyvoices.org/states)
  - » **Parent to Parent-USA** | Visit website: [www.p2pusa.org](http://www.p2pusa.org)
  - » **Partnerships for Parents** | Visit website: [partnershipforparents.net/](http://partnershipforparents.net/)

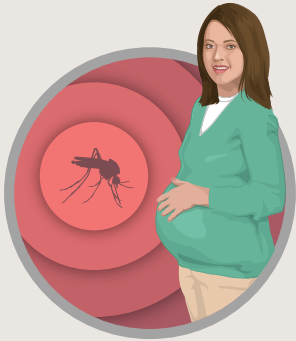
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For a more complete list of resources for families, please visit [www.cdc.gov/zika/parents/families-of-newborns-affected-zika.html](http://www.cdc.gov/zika/parents/families-of-newborns-affected-zika.html)

## REPORTING

# US ZIKA PREGNANCY REGISTRY

## Pediatric Healthcare Providers: How to Participate



**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 among pregnant women with laboratory evidence of Zika virus infection and their infants. 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 to their state, tribal, local, or territorial health department for possible testing; you may contact [zikapregnancy@cdc.gov](mailto:zikapregnancy@cdc.gov) to receive US Zika Pregnancy Registry State Health Department contact information.
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 to Report to the Registry

Infants are eligible for inclusion in the US Zika Pregnancy Registry if they are born in a US state or territory (with the exception of Puerto Rico) and are either: 1) born to a woman with laboratory evidence of possible Zika virus infection (regardless of whether she has symptoms, or 2) infants with laboratory evidence of possible congenital Zika virus infection (regardless of whether they have symptoms).

[www.cdc.gov/zika](http://www.cdc.gov/zika)



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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 infants with congenital Zika virus infection or with periconceptional, prenatal, or perinatal exposure. Information about these infants should be reported to the state, tribal, local, or territorial health department and are eligible to be included in 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 information to the Puerto Rico Zika Active Pregnancy Surveillance System (ZAPSS) rather than to the US Zika Pregnancy Registry.<sup>1</sup>

## How To Report to the Registry

- Healthcare providers should contact their state, tribal, local, or territorial health department to arrange for laboratory testing for Zika virus infection if the infant meets the clinical criteria for testing as outlined in the [CDC guidelines](#).
- Healthcare providers can contact CDC (call CDC's Emergency Operations Center watch desk at 770-488-7100; email [ZikaPregnancy@cdc.gov](mailto:ZikaPregnancy@cdc.gov); or fax 404-718-1013) to discuss information on infants suspected of having 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

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 164.528), individuals have the right to request from covered entities (i.e., you, the healthcare provider) an accounting of the disclosures of their protected health information.

You may wish to use the fact sheet for [pregnant women](#) to let your patients know how their information is being used. This fact sheet also contains information on the Assurance of Confidentiality that CDC has obtained. The Assurance is a formal confidentiality protection authorized under Section 308 (d) of the Public Service Act. Under this Assurance, identifiable information about your patient and the care you provide can only be used to better understand Zika virus infection during pregnancy and its outcomes. CDC cannot share it with anyone without your permission and your patient's permission, even if an official of the court, the government or law requests it.

## More Information about Zika

For more information, visit CDC's website [www.cdc.gov/zika](http://www.cdc.gov/zika). If families would like to speak to someone about a possible Zika virus infection or diagnosis during pregnancy, MotherToBaby experts are available to answer questions in English or Spanish by phone, email, or chat: [www.MotherToBaby.org](http://www.MotherToBaby.org). The free and confidential service is available Monday - Friday from 8am - 5pm (local time).

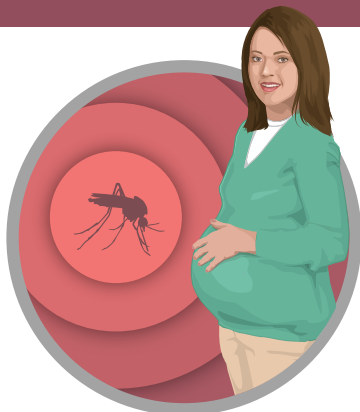
<sup>1</sup> Puerto Rico is establishing a separate Zika Active Pregnancy Surveillance System (ZAPSS)

## 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>

# 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 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 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 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 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 child's 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](http://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 ([www.cdc.gov/dcs/ContactUs/Form](http://www.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](http://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.



**U.S. Department of Health and Human Services**  
Centers for Disease Control and Prevention

## Additional Resources

### Testing for Zika Virus

The following links provide more information about how and when to test for Zika virus:

- [When to Test for Zika Virus](#)
- [Diagnostic Tests for Zika Virus](#)
- [Guidance for US Laboratories Testing for Zika Virus Infection](#)
- [Understanding Zika Virus Test Results](#)
- [Interim Guidance for Interpretation of Zika Virus Antibody Test Results](#)

### Reporting and Infant Follow-up

Healthcare providers should report infants with laboratory evidence of possible Zika virus infection (regardless of whether they have symptoms). If available, data should be collected at the time of initial identification and at 2, 6, and 12 months of age. More information about data reporting, collection, and findings can be found [here](#).

### Grand Rounds Toolkit for Pediatricians

This [presentation](#) and [facilitated discussion guide](#) provides an overview of Zika virus diagnostic testing, definitions, guidelines, patient counseling, and suggestions for reporting.

### Resources and Publications

- Measuring Head Circumference [Video](#)
- US Zika Pregnancy [Registry Inclusion Criteria](#)

