

THE U.S. ZIKA PREGNANCY REGISTRY

DATA SUBMISSION PROCESS

Infant Follow-up Form

The California Department of Public Health (CDPH) is participating in the U.S. Zika Pregnancy Registry and is the point of contact for California data submission to the Centers for Disease Control and Prevention (CDC).

Who Is Eligible for the Registry?

- Pregnant women in the United States with laboratory evidence of Zika virus infection (positive or equivocal test results, regardless of whether they have symptoms) and periconceptionally, prenatally, or perinatally exposed infants born to these women.
- Infants with laboratory evidence of congenital Zika virus infection (positive or equivocal test results, regardless of whether they have symptoms) and their mothers.

To participate, follow the directions below:

Healthcare Provider Instructions	Local Health Department Instructions
<ul style="list-style-type: none"> ▪ Healthcare providers should contact their Local Health Department (LHD) for questions about data submission. ▪ Providers may be contacted by either the LHD or CDPH for Zika pregnancy and infant outcomes data collection. ▪ Click here for more information on reporting Zika pregnancy and infant outcomes to CDPH. 	<ul style="list-style-type: none"> ▪ Local Health Departments may choose to follow up with healthcare providers or ask CDPH staff to follow-up. LHDs should inform CDPH of the LHD preference at: ZikaOutcomes@cdph.ca.gov. ▪ Various methods (e.g., medical record abstraction, telephone interview) can be used to collect surveillance information for the Registry. ▪ LHDs contacting providers to complete the attached form should insert the LHD contact information below for provider submission. ▪ LHDs should ensure completion of the attached form and then submit to CDPH by e-mail or fax as instructed below.

FORM PROCESSING INSTRUCTIONS

Send this form to:

California Department of Public Health

Fax: (510) 620-3152

Phone: (510) 620-3151

Email: ZikaOutcomes@cdph.ca.gov (Please send a message for instructions **before** submission).

My Local Health Department at the address below:

Phone: _____

Security note:

-Call prior to faxing forms to CDPH or Local Health Department.

-Please **DO NOT** scan and email documents before receiving instructions.

HIPAA Privacy Rule permits providers to disclose PHI without authorization to public health authorities for the purposes of preventing or controlling disease.

The CDPH California Birth Defects Monitoring Program (CBDMP) is authorized to conduct studies to investigate the causes of birth defects (H&S section 103840).



Infant's State/Territory ID _____ Registry ID _____
 Mother's State/Territory ID _____



U.S. Zika Pregnancy Registry Infant Follow-Up Form

These data are considered confidential and will be stored in a secure database at the Centers for Disease Control and Prevention

Please return completed form via SAMS or secure FTP—request access from ZIKApregnancy@cdc.gov

The form can also be sent by encrypted email to this address or by secure fax to **404-718-1013** or **404-718-2200**

Infant follow up: <input type="checkbox"/> 2 months <input type="checkbox"/> 6 months <input type="checkbox"/> 12 months <input type="checkbox"/> ___ months			
IFU.1. State/Territory reporting _____		IFU.2. Date of infant examination _____	
IFU.3. Infant's State/Territory ID _____	IFU.4. Mother's State/Territory ID _____	IFU.5. DOB: _____	IFU.6. Sex: <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Ambiguous/undetermined
IFU.7. Infant Death: <input type="checkbox"/> No <input type="checkbox"/> Yes		IFU.8. If yes, cause of death _____	
IFU.9. If yes, Date _____ or Age at death _____ <input type="checkbox"/> Unknown			
IFU.10. Weight: _____ grams or _____ lbs _____ oz	IFU.11. Length: _____ cm or _____ in	IFU.12. Head circumference: _____ cm or _____ in	
<p>IFU.13. Infant findings for corrected age at examination: <i>(For infants born preterm, please account for corrected age: chronological age minus weeks born before 40 weeks' gestation)</i></p> <p>Check all that apply</p> <p><input type="checkbox"/> Normal <input type="checkbox"/> Microcephaly (head circumference <3%ile)</p> <p><input type="checkbox"/> Fetal brain disruption sequence (collapsed skull, overlapping sutures, prominent occipital bone, scalp rugae)</p> <p><input type="checkbox"/> Anencephaly/ acrania <input type="checkbox"/> Encephalocele <input type="checkbox"/> Spina bifida</p> <p><input type="checkbox"/> Holoprosencephaly/arhinencephaly <input type="checkbox"/> Microphthalmia/Anophthalmia</p> <p><input type="checkbox"/> Hypertonia/Spasticity <input type="checkbox"/> Hyperreflexia <input type="checkbox"/> Irritability <input type="checkbox"/> Tremors</p> <p><input type="checkbox"/> Splenomegaly <input type="checkbox"/> Hepatomegaly <input type="checkbox"/> Skin rash</p> <p><input type="checkbox"/> Swallowing/feeding difficulties</p> <p><input type="checkbox"/> Arthrogryposis (congenital joint contractures)</p> <p><input type="checkbox"/> Congenital talipes equinovarus (clubfoot)</p> <p><input type="checkbox"/> Congenital hip dislocation/developmental dysplasia of the hip</p> <p><input type="checkbox"/> Other abnormalities</p> <p>IFU.14. Please list other abnormal findings:</p> 			
<p>IFU.15. Development assessment for corrected age at examination: <i>(For infants born preterm, please account for corrected age: chronological age minus weeks born before 40 weeks' gestation)</i></p> <p><input type="checkbox"/> Normal <input type="checkbox"/> Abnormal <input type="checkbox"/> Unknown</p> <p>IFU.16. If developmental delay, in what area? Please check all that apply</p> <p><input type="checkbox"/> Gross motor <input type="checkbox"/> Fine motor <input type="checkbox"/> Cognitive, linguistic and communication <input type="checkbox"/> Socio-Emotional</p>			
Special Studies Since Last Follow-up			
<p>IFU.17. Imaging study: <input type="checkbox"/> Cranial ultrasound <input type="checkbox"/> MRI <input type="checkbox"/> CT <input type="checkbox"/> Other _____</p> <p><input type="checkbox"/> Not Performed <input type="checkbox"/> Unknown</p>			

Infant's State/Territory ID _____ Registry ID _____
Mother's State/Territory ID _____

IFU.18. Date: _____

IFU.19. Findings: *check all that apply* Normal

- Microcephaly Intracranial calcifications Cerebral/cortical atrophy
 Abnormal cortical gyral patterns (lissencephaly, pachygyria, agyria, microgyria, polymicrogyria, schizencephaly)
 Corpus callosum abnormalities Cerebellar abnormalities Porencephaly
 Hydranencephaly Moderate or severe ventriculomegaly/hydrocephaly
 Fetal Brain Disruption Sequence (collapsed skull, overlapping sutures, prominent occipital bone, scalp rugae)
 Other major brain abnormalities
 Encephalocele Holoprosencephaly/ arhinencephaly
 Other abnormalities

IFU.20. *Please describe below*

IFU.21. Imaging study: Cranial ultrasound MRI CT Other _____

Not Performed Unknown

IFU.22. Date: _____

IFU.23. Findings: *check all that apply* Normal

- Microcephaly Intracranial calcifications Cerebral/cortical atrophy
 Abnormal cortical gyral patterns (lissencephaly, pachygyria, agyria, microgyria, polymicrogyria, schizencephaly)
 Corpus callosum abnormalities Cerebellar abnormalities Porencephaly
 Hydranencephaly Moderate or severe ventriculomegaly/hydrocephaly
 Fetal brain disruption sequence (collapsed skull, overlapping sutures, prominent occipital bone, scalp rugae)
 Other major brain abnormalities
 Encephalocele Holoprosencephaly/ arhinencephaly
 Other abnormalities

IFU.24. *(please describe below)*

IFU.25. Hearing screening or re-screening: Not performed Performed Unknown

IFU.26. *If performed:* Date: _____ **IFU.27.** Pass Fail or referred,

IFU.28. *Please describe*

IFU.29. Audiological evaluation: Not performed Performed Unknown

IFU.30. *If performed:* Date: _____ **IFU.31.** Normal Abnormal,

IFU.32. *Please describe*

Infant's State/Territory ID _____ Registry ID _____
Mother's State/Territory ID _____

IFU.33. Retinal exam (with dilation): Not Performed Performed Unknown

IFU.34. *If performed:* Date: _____

IFU.35. Findings: *Check all that apply:*

- Microphthalmia/anophthalmia Coloboma Cataract Intraocular calcifications
 Chorioretinal atrophy, scarring, macular pallor, gross pigmentary mottling, or retinal hemorrhage, excluding retinopathy of prematurity Other retinal abnormalities
 Optic nerve atrophy, pallor Other optic nerve abnormalities

IFU.36. *Please describe*

IFU.37. Other abnormal tests/results/diagnosis (include dates): No Yes

IFU.38. Date: _____

IFU.39. *Please describe*

Health Department Information

IFU.40. Name of person completing form: _____

IFU.41. Phone: _____ **IFU.42.** Email: _____

IFU.43. Date of form completion _____

Internal use only

Date entered _____

Data Entry Notes:

Data Entry POC Initials: _____

Public reporting burden of this collection of information is estimated to average 15 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer, 1600 Clifton Road NE, MS E-11, Atlanta, Georgia 30333; ATTN: PRA (0920-1101)