THE U.S. ZIKA PREGNANCY REGISTRY
CALIFORNIA 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).

If you require this document in an alternate format, please contact ZikaOutcomes@cdph.ca.gov.

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
▪ 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. ▪ Visit the US Zika Pregnancy Registry webpage for more information on reporting Zika pregnancy and infant outcomes to CDPH.	▪ 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 Registry forms directly 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 Registry forms 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).

California Department of PublicHealth

 REDCap ID_____ Infant ID_____

Reset Form

U.S. Zika Pregnancy and Infant 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 secure fax to 510-620-3152 or encrypted email to ZikaOutcomes@cdph.ca.gov

1. General, Growth and Travel Information

Infant follow up: ☐ 2 months ☐ 6 months ☐ 12 months ☐ 18 months ☐ 24 months ☐_____months

IFU.1. State/Territory reporting: Select State

IFU.2. Infant's State/Territory ID	**IFU.3.** Mother's State/Territory ID	**IFU.4.** DOB:	**IFU.5.** Sex: ☐ Male ☐ Female ☐ Ambiguous/undetermined
_____	_____	_____	

Infant death

IFU.6. Infant Death: ☐ No ☐ Yes

IFU.7. If yes, cause of death: _____

IFU.8. If yes, date of death:_____ or Age at death_____ ☐ Unknown/Not stated

Growth

IFU.9. Weight: _____ grams **or** _____lbs____oz **IFU.10.** Date of measurement: _____	**IFU.11.** Length: _____ cm **or** _____in **IFU.12.** Date of measurement: _____	**IFU.13.** Head circumference: _____ cm **or** _____in **IFU.14.** Date of measurement: _____

Optional Section
Postnatal travel *Only complete if infant received PRNT testing*

IFU.15. Postnatal travel to an area with active Zika virus transmission *mark one* ☐ Yes ☐ No ☐ Unknown/Not stated

IFU.16. Location of exposure (1) _____	**IFU.17**. Start Date _____	**IFU.18**. End Date _____
IFU.19. Location of exposure (2) _____	**IFU.20**. Start Date _____	**IFU.21**. End Date _____
IFU.22. Location of exposure (3) _____	**IFU.23**. Start Date _____	**IFU.24**. End Date _____

2. Neurologic Sequelae

Physical exam or neurological evaluation

IFU.25. Physical exam or neurological evaluation performed: *mark one*

- ☐ Yes - *If "Yes", complete the section below*
- ☐ No - *If "No", skip to* ***"Developmental Assessment" (page 3)***
- ☐ Unknown/Not Stated – *If "Unknown/Not stated", skip to* ***"Developmental Assessment" (page 3)***

IFU.26. Date of exam or evaluation: _____

IFU.27. Findings from physical exam or neurological evaluation: *check all that apply*

☐ Normal

Neurologic sequelae

- ☐ Seizures

Body tone abnormalities

- ☐ Hypertonia/spasticity
- ☐ Hyperreflexia
- ☐ Hypotonia

Movement abnormalities

- ☐ Dyskinesia or dystonia
- ☐ Tremors

- ☐ Swallowing/feeding difficulties

Signs of possible visual impairment

- ☐ Failure to fix and follow
- ☐ Nystagmus
- ☐ Esotropia/Strabismus

- ☐ Irritability

Contractures with brain anomalies

- ☐ Arthrogryposis (congenital joint contractures)
- ☐ Congenital talipes equinovarus (clubfoot)
- ☐ Congenital hip dislocation/developmental dysplasia of the hip

☐ Fetal brain disruption sequence

- ☐ Collapsed skull/ prominent occipital bone
- ☐ Scalp rugae/ excessive scalp skin

☐ Other abnormalities - *Please describe:*

IFU.28. Describe findings identified in **IFU.27.**:

3. Developmental Assessment

IFU.29. Overall interpretation of development: *mark one*

☐ Normal - *If "Normal", complete the section below*

☐ Abnormal - *If "Abnormal", complete the section below*

☐ Unknown/Not stated - *If "Unknown/Not stated", skip to* ***"Neurological Imaging Studies" (page 4)***

IFU.30. Date of exam: _____

IFU.31. Areas of developmental delay: *check all that apply* ☐ No delays

☐ Gross motor ☐ Fine motor ☐ Cognitive- linguistic and communication ☐ Socio-Emotional

IFU.32. Describe all abnormal findings:

IFU.33. Standardized developmental assessment or evaluation performed: *mark one*

☐ Yes *If "Yes",* **IFU.34.** Type of assessment: _____

☐ No

☐ Unknown/Not stated

4. Neurological Imaging Studies – findings of congenital anomalies of the brain/spinal cord

IFU.35. Neurological imaging studies performed: *mark one*

☐ Yes - *If "Yes", complete the section below*

☐ No - *If "No", skip to* ***"Audiological Screening and Evaluation" (page 5)***

☐ Unknown/Not stated - *If "Unknown/Not stated", skip to* ***"Audiological Screening and Evaluation" (page 5)***

IFU.36. Neurological imaging type: *mark one* ☐ Cranial ultrasound ☐ MRI ☐ CT

☐ Other: _____

IFU.37. Date of imaging: _____

IFU.38. Findings from neurological imaging study: *check all that apply*

☐ Normal
☐ Microcephaly
☐ Intracranial calcifications
☐ Cerebral/cortical atrophy
☐ Abnormal cortical formation
(polymicrogyria, lissencephaly, pachygyria, schizencephaly, gray matter heterotopia, agyria, microgyria)
☐ Corpus callosum abnormalities
☐ Cerebellar abnormalities
☐ Porencephaly
☐ Hydranencephaly
☐ Moderate or severe ventriculomegaly/hydrocephaly
☐ Encephalocele
☐ Holoprosencephaly/ arhinencephaly
☐ Other abnormalities - *Please describe:*

IFU.39. Describe all findings identified in **IFU.38.**:

IFU.40. Neurological imaging type: *mark one* ☐ Cranial ultrasound ☐ MRI ☐ CT

☐ Other: _____

IFU.41. Date of imaging: _____

IFU.42. Findings from neurological imaging study: *check all that apply*

☐ Normal
☐ Microcephaly
☐ Intracranial calcifications
☐ Cerebral/cortical atrophy
☐ Abnormal cortical formation
(polymicrogyria, lissencephaly, pachygyria, schizencephaly, gray matter heterotopia, agyria, microgyria)
☐ Corpus callosum abnormalities
☐ Cerebellar abnormalities
☐ Porencephaly
☐ Hydranencephaly
☐ Moderate or severe ventriculomegaly/hydrocephaly
☐ Encephalocele
☐ Holoprosencephaly/ arhinencephaly
☐ Other abnormalities - *Please describe:*

IFU.43. Describe all findings identified in **IFU.42.**:

5. Audiological Screening and Evaluation

Hearing screening or re-screening, excluding birth hospitalization hearing screening

IFU.44. Hearing screening performed: *mark one*

☐ Yes - *If "Yes", complete the section below*

☐ No - *If "No", skip to* ***"Audiological evaluation" (page 5)***

☐ Unknown/Not stated - *If "Unknown/Not Stated", skip to* ***"Audiological Evaluation" (page 5)***

IFU.45. Date of screening: _____

IFU.46. Hearing screening results: *mark one*

☐ Pass ☐ Fail or referred ☐ Unknown/Not stated

IFU.47. If hearing screening failed, specify: *mark one*

☐ Abnormal, unilateral ☐ Abnormal, bilateral ☐ Abnormal, laterality unknown/not stated

IFU.48. Provide any additional comments from hearing screening:

Audiological evaluation

IFU.49. Audiological evaluation performed: *mark one*

☐ Yes - *If "Yes", complete the section below*

☐ No - *If "No", skip to* ***"Congenital Anomalies of the Eye" (page 6)***

☐ Unknown/Not stated - *If "Unknown/Not Stated", skip to* ***"Congenital Anomalies of the Eye" (page 6)***

IFU.50. Date of evaluation: _____

IFU.51. Overall interpretation of audiological evaluation: *mark one* ☐ Unknown/Not stated

☐ Normal ☐ Abnormal, unilateral ☐ Abnormal, bilateral ☐ Abnormal, laterality not stated

IFU.52. If overall interpretation is abnormal, indicate type(s) of hearing loss and severity of hearing loss: *mark all that apply*

Type of hearing loss – mark all that apply

☐ Conductive hearing loss
☐ Sensorineural hearing loss
☐ Mixed hearing loss
☐ Auditory neuropathy spectrum disorder
☐ Hearing loss, type unknown/not stated

Severity of hearing loss – mark all that apply

☐ Mild
☐ Moderate
☐ Moderately severe
☐ Severe
☐ Profound
☐ Severity unknown/not stated

IFU.53. Provide any additional comments from audiological evaluation:

6. Congenital Anomalies of the Eye

IFU.54. Retinal exam: *mark one*

☐ Yes - *If "Yes", complete the section below*

☐ No - *If "No", skip to* ***"Additional Studies and Evaluation" (page 7)***

☐ Unknown/Not stated - *If "Unknown/Not stated", skip to* ***"Additional Studies and Evaluation" (page 7)***

IFU.55. Date of exam: _____

IFU.56. Overall eye findings: *mark one* ☐ Unknown/Not stated

☐ Normal ☐ Abnormal, unilateral ☐ Abnormal, bilateral ☐ Abnormal, laterality not stated

IFU.57. Visual acuity/impairment: *mark one* ☐ Unknown/Not stated

☐ Normal ☐ Abnormal, unilateral ☐ Abnormal, bilateral ☐ Abnormal, laterality not stated

IFU.58. If eye findings are abnormal, indicate all abnormal findings: *check all that apply*

☐ Microphthalmia/anophthalmia
☐ Cataract
☐ Intraocular calcifications
☐ Coloboma
  ☐ Coloboma of the iris
  ☐ Coloboma of the retina or optic nerve
☐ Chorioretinal anomalies involving the macula (e.g., chorioretinal atrophy and scarring, macular pallor, gross pigmentary mottling)
☐ Optic nerve atrophy, pallor
☐ Other optic nerve abnormalities **-** *Please describe*:

IFU.59. Describe all findings identified in **IFU.56.– IFU.58.**:

7. Additional Studies and Evaluation

IFU.60. Other studies performed: *mark one*

☐ Yes - *If "Yes", complete the section below*

☐ No - *If "No", skip to* ***"Health Department Information" (page 7)***

☐ Unknown/Not stated - *If "Unknown/Not stated", skip to* ***"Health Department Information" (page 7)***

IFU.61. Study type: *mark one* ☐ Electroencephalogram (EEG) ☐ Swallowing evaluation ☐ Hip ultrasound ☐ Other:_____

IFU.62. Date of study: _____

IFU.63. Overall interpretation: *mark one* ☐ Normal ☐ Abnormal ☐ Unknown/Not stated

IFU.64. Describe abnormal findings:

IFU.65. Study type: *mark one* ☐ Electroencephalogram (EEG) ☐ Swallowing evaluation ☐ Hip ultrasound ☐ Other:_____

IFU.66. Date of study: _____

IFU.67. Overall interpretation: *mark one* ☐ Normal ☐ Abnormal ☐ Unknown/Not stated

IFU.68. Describe abnormal findings:

8. Health Department Information

Name of person completing form: _____

Phone: _____ Email: _____

Date of form completion: _____

Internal use only

Date entered_____ ***Data Entry POC Initials:***	***Data Entry Notes*:**

END