

## 09-ID-61

**Committee:** Infectious

**Title:** Public Health Reporting and National Notification for Congenital Rubella Syndrome

### I. Statement of the Problem

CSTE position statement 07-EC-02 recognized the need to develop an official list of nationally notifiable conditions and a standardized reporting definition for each condition on the official list. The position statement also specified that each definition had to comply with American Health Information Community recommended standards to support “automated case reporting from electronic health records or other clinical care information systems.” In July 2008, CSTE identified sixty-eight conditions warranting inclusion on the official list, each of which now requires a standardized reporting definition.

### II. Background and Justification

#### *Background<sup>1</sup>*

While rubella has been eliminated from the United States, a low number of cases of congenital rubella syndrome continue to occur in the US. Infants with congenital rubella syndrome are typically born to mothers who were born outside the United States and were never vaccinated during childhood. These women may be exposed to rubella while traveling home to countries where rubella remains endemic or when rubella virus circulates for a limited period following introduction into an under immunized immigrant community. Surveillance for congenital rubella syndrome is necessary to document the incidence of infection and to define high-risk populations for intervention.

#### *Justification*

Congenital rubella syndrome meets the following criteria for a nationally and **standard** notifiable condition, as specified in CSTE position statement 08-EC-02:

- A majority of state and territorial jurisdictions—or jurisdictions comprising a majority of the US population—have laws or regulations requiring **standard** reporting of Congenital rubella syndrome to public health authorities
- CDC requests **standard** notification of Congenital rubella syndrome to federal authorities
- CDC has condition-specific policies and practices concerning the agency’s response to, and use of, notifications.

---

<sup>1</sup> Much of the material in the background is directly quoted from the CDC’s congenital rubella syndrome Website. See the References for further information on this source.

### III. Statement of the desired action(s) to be taken

CSTE requests that CDC adopt this standardized reporting definition for Congenital rubella syndrome to facilitate more timely, complete, and standardized local and national reporting of this condition.

### IV. Goals of Surveillance

To provide information on the temporal, geographic, and demographic occurrence of Congenital rubella syndrome to facilitate its prevention and control.

### V. Methods for Surveillance

Surveillance for Congenital rubella syndrome should use the sources of data and the extent of coverage listed in table V.

**Table V.** Recommended sources of data and extent of coverage for ascertaining cases of Congenital rubella syndrome.

Source of data for case ascertainment	Coverage	
	Population-wide	Sentinel sites
clinician reporting	X	
laboratory reporting	X	
reporting by other entities (e.g., hospitals, veterinarians, pharmacies)	X	
death certificates	X	
hospital discharge or outpatient records	X	
extracts from electronic medical records		
telephone survey		
school-based survey		
other _____		

### VI. Criteria for Reporting

Reporting refers to the process of healthcare providers or institutions (e.g., clinicians, clinical laboratories, hospitals) submitting basic information to governmental public health agencies about cases of illness that meet certain reporting requirements or criteria. Cases of illness may also be ascertained by the secondary analysis of administrative health data or clinical data. The purpose of this section is to provide those criteria to determine whether a specific illness should be reported.

## **A. Narrative description of criteria to determine whether a case should be reported to public health authorities**

Report any illness to public health authorities that meets any of the following criteria:

1. Any infant with any of the following laboratory indicators of rubella infection:
  - a. a positive culture for rubella virus from a clinical specimen
  - b. a positive rubella IgM test
  - c. PCR positive for rubella virus
  - d. a persistently high rubella antibody test.
2. Any infant with 2 or more of the following clinical findings compatible with congenital rubella syndrome, and for which no alternate cause is evident:
  - a. cataracts or congenital glaucoma
  - b. congenital heart disease (most commonly patent ductus arteriosus or peripheral pulmonary artery stenosis)
  - c. hearing impairment
  - d. pigmentary retinopathy
  - e. purpura
  - f. hepatosplenomegaly
  - g. jaundice
  - h. microcephaly
  - i. developmental delay
  - j. meningoencephalitis
  - k. radiolucent bone disease
3. Any infant born to a mother with a history of rubella during pregnancy.
4. Any infant diagnosed by a physician as having congenital rubella syndrome.

### *Other recommended reporting procedures*

- All cases of congenital rubella syndrome should be reported.
- Reporting should be on-going and routine.
- Frequency of reporting should follow the state health department's routine schedule.

## **B. Table of criteria to determine whether a case should be reported to public health authorities**

**Table VI-B.** Table of criteria to determine whether a case should be reported to public health authorities. Requirements for reporting are established under State and Territorial laws and/or regulations and may differ from jurisdiction to jurisdiction. These criteria are suggested as a standard approach to identifying cases of this condition for purposes of reporting, but reporting should follow State and Territorial law/regulation if any conflicts occur between these criteria and those laws/regulations.

<b>Criterion</b>	<b>Reporting</b>	
<i>Clinical Presentation</i>		
Cataracts or congenital glaucoma		O†
Congenital heart disease		O†
Hearing impairment		O†
Pigmentary retinopathy		O†
Purpura		O†
Hepatosplenomegaly		O†
Jaundice		O†
Microcephaly		O†
Developmental delay		O†
Meningoencephalitis		O†
Radiolucent bone disease		O†
Physician diagnosis of congenital rubella syndrome	S	
<i>Laboratory findings</i>		
Rubella virus isolated from a clinical specimen	S	
Rubella IgM test positive	S	
PCR positive for Rubella virus	S	
Persistently high Rubella antibody titer	S	
<i>Epidemiological risk factors</i>		
Maternal rubella during pregnancy	S	

Notes:

S = This criterion alone is sufficient to report a case

O† = For congenital rubella syndrome, at least two of the clinical “O” criteria are required to report a case.

### **C. Disease Specific Data Elements:**

Disease-specific data elements to be included in the initial report are listed below.

#### *Epidemiological Risk Factors*

Country of Mother’s birth

Country of Child’s birth

Maternal Travel History During Pregnancy

Maternal Rubella Immunization History

Maternal Rubella Serology Result(s) with Dates

History of Maternal Illness During Pregnancy

Fever (Date of Onset, Duration)

Rash (Date of Onset, Duration)

Maternal Contact to Persons with Rash Illness, Dates

## **VII. Case Definition for Case Classification**

### **A. Narrative description of criteria to determine whether a case should be classified as confirmed, probable (presumptive), suspected (possible).**

#### **Case classification**

*Suspected Case:* An infant who does not meet the criteria for a probable or confirmed case but who has one of more of the following clinical findings:

- cataracts
- congenital glaucoma
- congenital heart disease (most commonly patent ductus arteriosus or peripheral pulmonary artery stenosis)
- hearing impairment
- pigmentary retinopathy
- purpura
- hepatosplenomegaly
- jaundice
- microcephaly
- developmental delay
- meningoencephalitis, or
- radiolucent bone disease

*Probable Case:* An infant who does not have laboratory confirmation of rubella infection but has at least 2 of the following, without a more plausible etiology:

- cataracts or congenital glaucoma,\*
- congenital heart disease (most commonly patent ductus arteriosus or peripheral pulmonary artery stenosis),
- hearing impairment, or
- pigmentary retinopathy;

OR

An infant who does not have laboratory confirmation of rubella infection but has at least one or more of the following, without a more plausible etiology:

- cataracts or congenital glaucoma,\*
- congenital heart disease (most commonly patent ductus arteriosus or peripheral pulmonary artery stenosis),
- hearing impairment, or
- pigmentary retinopathy

AND one or more of the following:

- purpura,
- hepatosplenomegaly,
- jaundice,
- microcephaly,
- developmental delay,
- meningoencephalitis, or
- radiolucent bone disease.

**Confirmed Case:** An infant with one at least one of the symptoms clinically consistent with congenital rubella syndrome listed above; and laboratory evidence of congenital rubella infection as demonstrated by:

- isolation of rubella virus, or
- detection of rubella-specific immunoglobulin M (IgM) antibody, or
- infant rubella antibody level that persists at a higher level and for a longer period than expected from passive transfer of maternal antibody (i.e., rubella titer that does not drop at the expected rate of a twofold dilution per month), or
- a specimen that is PCR positive for rubella virus.

**Infection only:** An infant without any clinical symptoms or signs of rubella but with laboratory evidence of infection as demonstrated by

- isolation of rubella virus, or
- detection of rubella-specific immunoglobulin M (IgM) antibody, or
- infant rubella antibody level that persists at a higher level and for a longer period than expected from passive transfer of maternal antibody (i.e., rubella titer that does not drop at the expected rate of a twofold dilution per month), or
- a specimen that is PCR positive for rubella virus.

\*In probable cases, either or both of the eye-related findings (cataracts and congenital glaucoma) count as a single complication. In cases classified as infection only, if any compatible signs or symptoms (e.g., hearing loss) are identified later, the case is reclassified as confirmed.

### **Epidemiologic Classification of Internationally-Imported and U.S.-Acquired**

Congenital rubella syndrome cases will be classified epidemiologically as internationally imported or U.S.-acquired, according to the source of infection in the mother, using the definitions below, which parallel the classifications for rubella cases.

*Internationally imported case:* To be classified as an internationally imported CRS case, the mother must have acquired rubella infection outside the U.S. or in the absence of documented rubella infection, the mother was outside the United States during the period when she may have had exposure to rubella that affected her pregnancy (from 21 days before conception and through the first 24 weeks of pregnancy).

*U.S.-acquired case:* A US-acquired case is one in which the mother acquired rubella from an exposure in the United States. U.S.-acquired cases are subclassified into four mutually exclusive groups:

**Import-linked case:** Any case in a chain of transmission that is epidemiologically linked to an internationally imported case.

**Import-virus case:** a case for which an epidemiologic link to an internationally imported case was not identified but for which viral genetic evidence indicates an imported rubella genotype, i.e., a genotype that is not occurring within the United States in a pattern indicative of endemic transmission. An endemic genotype is the genotype of any rubella virus that occurs in an endemic chain of transmission (i.e., lasting  $\geq 12$  months). Any genotype that is found repeatedly in U.S.-acquired cases should be thoroughly investigated as a potential endemic genotype, especially if the cases are closely related in time or location.

**Endemic case:** a case for which epidemiological or virological evidence indicates an endemic chain of transmission. Endemic transmission is defined as a chain of rubella virus transmission continuous for  $\geq 12$  months within the United States.

**Unknown source case:** a case for which an epidemiological or virological link to importation or to endemic transmission within the U.S. cannot be established after a thorough investigation. These cases must be carefully assessed epidemiologically to assure that they do not represent a sustained U.S.-acquired chain of transmission or an endemic chain of transmission within the U.S.

**Note:** Internationally imported, import-linked, and imported-virus cases are considered collectively to be import-associated cases.

States may also choose to classify cases as “out-of-state-imported” when imported from another state in the United States. For national reporting, however, cases will be classified as either internationally imported or U.S.-acquired.

## **B. Classification Table**

Table VII-B lists the criteria that must be met for a case to be classified as confirmed, probable (presumptive), suspected (possible) or infection only.

**Table VII-B.** Table of criteria to determine whether a case is classified.

Criterion	Case Definition				
	Confirmed	Probable		Suspected	Infection Only
<i>Clinical Presentation</i>					
Group A					
Cataracts or congenital glaucoma	O	O†	O^	O	A
Congenital heart disease	O	O†	O^	O	A
Hearing impairment	O	O†	O^	O	A
Pigmentary retinopathy	O	O†	O^	O	A
Group B					
Purpura	O		O^	O	A
Hepatosplenomegaly	O		O^	O	A
Jaundice	O		O^	O	A
Microcephaly	O		O^	O	A
Developmental delay	O		O^	O	A
Meningoencephalitis	O		O^	O	A
Radiolucent bone disease	O		O^	O	A
<i>Laboratory findings</i>					
Rubella virus isolated from a clinical specimen	O				O
Rubella IgM test positive	O				O
PCR positive for Rubella virus	O				O
Persistently high Rubella antibody titer	O				O

Notes:

O = At least one of these “O” criteria in each category in the same column (e.g., clinical presentation and laboratory findings)—in conjunction with all other “N” criteria in the same column—is required to classify a case

O† = A minimum of 2 clinical findings from Group A are required.

O^ = A minimum of 1 clinical finding from Group A and 1 clinical finding from Group B are required.

## VIII. Period of Surveillance

Surveillance should be on-going.



## **IX. Data sharing/release and print criteria**

Notification to CDC for confirmed cases of congenital rubella is recommended.

- Data reported to NCIRD staff is summarized weekly internally via an NCIRD weekly surveillance report for vaccine preventable diseases. Electronic reports of congenital rubella syndrome (CRS) in NNDSS are also summarized weekly in the MMWR Tables. However, because of delays in data entry and data transmission via NNDSS, these two data sources may not correspond. Annual case data on CRS is used in the yearly Summary of Notifiable Diseases and monitored for meeting Healthy People 2010 goals.
- State-specific compiled data will continue to be published in the weekly NCIRD reports as well as annual MMWR Summaries of Notifiable Diseases. In addition to those reports, the frequency of reports/feedback to the states and territories will be dependent on the current epidemiologic situation surrounding the CRS patient. Given elimination of endemic rubella in the US., identifying the country during exposure is imperative. Frequency of cases, epidemiologic distribution, importation status, transmission risk to non-immune pregnant females will guide frequency and method of communication and information feedback.
- State-specific compiled data will continue to be published in the weekly reports and annual MMWR Surveillance Summaries. All cases are verified with the state (s) before publication. Data are also included in PAHO and WHO annual reports. The frequency of release of additional publication of this data will be dependent on the current epidemiologic situation in the country. These publications might include annual epidemiologic summaries in the MMWR or manuscripts in peer-reviewed journals.
- As part of an effort to maintain and document rubella elimination in the Americas, we will share data on CRS cases known to NCIRD with PAHO. CRS is endemic outside the Western Hemisphere, also in Argentina and Brazil. Although no longer endemic in the U. S., CRS continues to be identified due to importation. State Health Departments are notified when cases are identified communicable in their jurisdiction. CRS information will be shared with PAHO upon request such as sex, age, rash onset, clinical description, mother's country of birth, genotype and source (import, import-associated etc.). No personal identifying or state specific information is re-released to PAHO or WHO.

## **X. References**

Centers for Disease Control and Prevention (CDC). Case definitions for infectious conditions under public health surveillance. MMWR 1997; 46(No. RR-10):1–57. Available from: <http://www.cdc.gov/mmwr/>

Centers for Disease Control and Prevention (CDC). National notifiable diseases surveillance system: case definitions. Atlanta: CDC. Available from: <http://www.cdc.gov/ncphi/disss/nndss/casedef/index.htm> Last updated: 2008 Jan 9. Accessed:

Council of State and Territorial Epidemiologists (CSTE). CSTE official list of nationally notifiable conditions. CSTE position statement 07-EC-02. Atlanta: CSTE; June 2007. Available from: <http://www.cste.org>.

Council of State and Territorial Epidemiologists (CSTE). Criteria for inclusion of conditions on CSTE nationally notifiable condition list and for categorization as immediately or routinely notifiable. CSTE position statement 08-EC-02. Atlanta: CSTE; June 2008. Available from: <http://www.cste.org>.

Council of State and Territorial Epidemiologists (CSTE). Data Release Guidelines of the Council of State & Territorial Epidemiologists for the National Public Health System. Atlanta: CSTE; June 1996.

Council of State and Territorial Epidemiologists, Centers for Disease Control and Prevention. CDC-CSTE Intergovernmental Data Release Guidelines Working Group (DRGWG) Report: CDC-ATSDR Data Release Guidelines and Procedures for Re-release of State-Provided Data. Atlanta: CSTE; 2005. Available from: <http://www.cste.org/pdffiles/2005/drgwgreport.pdf> or <http://www.cdc.gov/od/foia/policies/drgwg.pdf>.

Heymann DL, editor. Control of communicable diseases manual. 18th edition. Washington: American Public Health Association; 2004.

Gershon AA. Rubella Virus (German Measles). In: Mandell GL, Bennett JE, Dolin R, editors. Principles and Practice of Infectious Diseases, 6th edition. Philadelphia: Churchill Livingstone; 2005.

## **XI. Coordination:**

### **Agencies for Response:**

- (1) Thomas R Frieden, MD, MPH  
Director  
Centers for Disease Control and Prevention  
1600 Clifton Road, NE  
Atlanta GA 30333  
(404) 639-7000  
txf2@cdc.gov

## **XII. Submitting Author:**

- (1) Paul Cieslak, MD  
Manager, Acute and Communicable Disease Prevention  
Oregon Department of Human Services  
800 NE Oregon St./Suite 772  
Portland, OR 97232  
(971) 673-1111  
paul.r.cieslak@state.or.us

## **Co-Authors:**

- (1) Associate Member  
Harry F. Hull, Medical Epidemiologist  
HF Hull & Associates, LLC  
1140 St. Dennis Court  
Saint Paul, MN 55116  
(651) 695-8114  
hullhf@msn.com
- (2) Associate Member  
Cecil Lynch, Medical Informaticist  
OntoReason  
7292 Shady Woods Circle  
Midvale, UT 84047  
(916) 412.5504  
clynch@ontoreason.com
- (3) Associate Member  
R. Gibson Parrish, Medical Epidemiologist  
P.O. Box 197  
480 Bayley Hazen Road  
Peacham, VT 05862  
(802) 592-3357  
gib.parrish@gmail.com