

# Identifying Unreported and Undiagnosed Cases of Congenital Syphilis in Arizona Using Live Birth and Fetal Death Registries

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**Abstract:** To investigate the drop in reported congenital syphilis cases from 28 in 2005 to 16 in 2006, the Arizona infant registries were cross matched with reported syphilis test among women in the state STD database. Six previously unreported cases were identified; four live births and two still births.

**Key Words:** syphilis, congenital syphilis, prenatal care, prenatal syphilis screening, cross-match

The tragedy of congenital syphilis (CS) is that with proper prenatal screening and adequate and timely treatment of pregnant women with syphilis, the disease is preventable in nearly every case.<sup>1</sup> Nonetheless, CS remains a present and devastating disease of the neonatal and early childhood periods. The national CS rates have been rising. In 2007, the country experienced a 15% increase in the rate of CS (9.1–10.5 cases per 100,000 live births).<sup>2</sup> At the state level, Arizona has had one of the top 5 highest annual rates of CS of 6 years during 2002–2007, including the highest rate in the country during the years 2003, 2004, and 2005.<sup>2–7</sup>

Between 2005 and 2006, the number of reported CS cases in Arizona decreased from 28 to 16 cases, representing a 43% decrease.<sup>6,7</sup> The number then increased in 2007 to its previously elevated levels with 30 cases.<sup>2</sup> To identify any unreported CS cases for the 2006 year, we cross-matched the state infant registries with the Arizona Department of Health Services (ADHS) sexually transmitted diseases (STD) database.

In Arizona, physicians and laboratories are mandated by state rule to report certain STDs to ADHS.<sup>8</sup> A cross-match was performed of all women reported to ADHS with positive syphilis-related laboratory tests (treponemal and nontreponemal)

from January 1, 2005 to December 31, 2007 with the 2006 Arizona live birth and fetal death registries. The first name, date of birth, and/or last name of women with positive syphilis labs in the STD database were cross-matched to the live birth database and fetal death database using maternal first name combined with either maternal last name, maiden name, date of birth, or fetal last name (Fig. 1). The cross matches were completed using Statistical Analysis Software version 9.1 and managed in Microsoft Excel 2003. This study methodology was based upon similar methods published from the New Mexico State Health Department.<sup>9</sup> Disease surveillance, data collection, evaluation, and analysis are ongoing public health surveillance activities and thus are not subject to review by institutional review boards.

Criteria for classification of CS cases were determined using the CDC Congenital Syphilis Cases Investigation and Report Form 73.126 and previously published criteria (1) a live born infant with signs of CS or in whom *Treponema pallidum* was identified from external lesions, placenta, umbilical cord, or autopsy specimens, or whose mother had a syphilitic lesion at delivery; (2) a live born infant delivered to a woman with untreated or inadequately treated syphilis before or during pregnancy; (3) a live born infant delivered to a woman with early syphilis whose serologic response to penicillin therapy was documented to be inadequate and who had either a radiologic and/or cerebrospinal fluid test consistent with CS (or the infant tests were not completed); or (4) a stillborn infant delivered to a woman with untreated or inadequately treated syphilis before or during pregnancy.<sup>10–12</sup> In addition, any baby was included as a case if a maternal positive nontreponemal test was obtained during pregnancy or at delivery, but the positive treponemal test was completed subsequently. Categories for reason for classification of those determined to be cases were assigned according to a previously published analysis from Arizona: treatment less than 30 days before delivery, lack of adequate titer decline, no treatment during pregnancy, and no prenatal test with a positive test at delivery.<sup>13</sup>

After cross-matching of the datasets, the final list of women with positive syphilis lab tests with matched live births or fetal deaths in 2006 was then evaluated on a case by case basis. All but two previously reported cases (both due to first and middle name ordering discrepancies) were identified through the cross-match. Available state and county health department field, interview, and reporting records were initially reviewed to identify infants that should be excluded from further review because their mothers were falsely positive for syphilis (positive nontreponemal with a negative treponemal test), or the previously described case criteria were not met. Possible CS cases then underwent a review of prenatal care and delivery medical charts for determination of CS case status.<sup>11</sup> Demographic information, including maternal age, race, county

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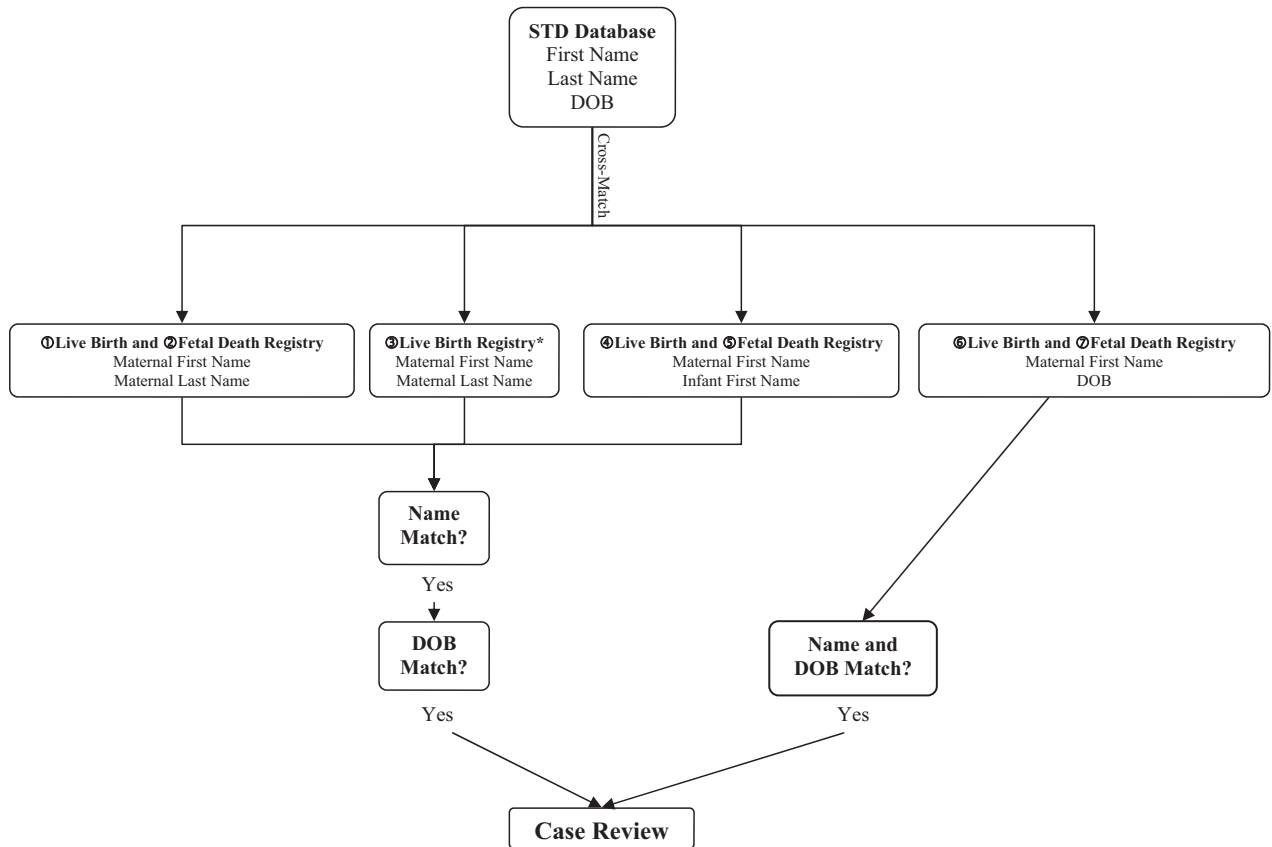
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\*2006 ADHS fetal death registry does not include maternal last name. As a result, the registry was not included in this cross-match.

Figure 1. ADHS STD database and ADHS live births/fetal deaths registry cross-match algorithm.

of residence, and maternal stage of syphilis was collected from health department record review. Gestational age, maternal and infant treatment, and infant clinical assessment were collected from medical chart review.

After the exclusion of previously reported congenital syphilis cases, the merge of the live births and the STD database resulted in the identification of twenty eight mother-infant pairs. Four of these infants were determined to be congenital syphilis cases (Table 1). The merge of the fetal deaths database and the ADHS STD database resulted in the identification of 3 mother-infant pairs. Two of these babies were classified as syphilitic stillbirth cases (Table 1).

Arizona continues to face the challenge of high congenital syphilis rates. The use of this cross-match method led to the identification and evaluation of 6 unreported cases of congenital syphilis. Two of the live birth infants were not treated at delivery. All 6 cases represent missed opportunities for diagnosis and prevention, health department case investigation, and provider reporting. The identification of these cases for Arizona in 2006 demonstrates the limitations of a passive surveillance system for these sentinel disease events. In addition, unreported congenital syphilis cases may represent gaps in provider knowledge about required reporting and/or proper diagnosis and treatment. This study highlights the need for more timely

TABLE 1. Summary of Identified Congenital Syphilis Cases (N = 6)

Infant Status	Maternal Race/Ethnicity	Maternal Age at Delivery (yr)	Gestational Age at Delivery (wk)	Category for Missed Case
Live birth	Hispanic	25	37	Treatment less than 30 days prior to delivery
Live birth	Native American	28	38	Lack of adequate titer decline
Live birth	Black	27	40	No treatment during pregnancy
Live birth	Hispanic	27	31	No prenatal test
Fetal demise	Hispanic	26	25	No prenatal test
Fetal demise	Hispanic	22	22	No prenatal test

and complete health department follow-up of positive syphilis tests among women in Arizona.

Congenital syphilis rates disproportionately affect minority and urban populations in Arizona.<sup>13,14</sup> All 6 of the cases identified in this cross-match were born to women in racial/ethnic minority groups, with 67% of the cases and both stillbirths occurring among Hispanic mothers. These results mirror the racial disparities seen among reported congenital syphilis cases in Arizona and underscore the challenges in improving access, uptake, and quality of early prenatal care in these populations.<sup>13,14</sup>

The use of birth registries to compare the demographics of mothers of uninfected infants to those of congenital syphilis infants have been described previously.<sup>15,16</sup> The utility of this cross-match method was demonstrated in this analysis as it identified currently reported cases as well as those that were unreported and/or undiagnosed. The reasons for diagnosis of these cases were similar to those identified in previous years and highlight missed opportunities for prevention.<sup>13,16</sup> Lack of prenatal care and late prenatal care, seen for 3 of these 6 cases, are common contributors to congenital syphilis due to the lack of timely diagnosis and treatment opportunities.<sup>16–19</sup> Health department intervention would not have prevented these cases. However, the maternal case that was treated less than 30 days before delivery would have benefited from health department intervention, which would have included testing and treatment recommendations for the infant at delivery. The case diagnosed due to a lack of adequate decline in titer after treatment would have benefited from health department intervention, which may have included recommendations for repeat testing after treatment to track decline in titer and initiation of retreatment if RPR titer drop was not timely. The remaining case reflected conflicting test results that reverted from positive to negative and then again to positive. Timely health department follow-up in this case would have included recommendations for treatment during pregnancy.

Limitations of passive surveillance for the identification of congenital syphilis were demonstrated from this cross-match of health department reporting registries. The addition of these six infants represents a 27% increase in the number of cases for 2006 and an annual rate per 100,000 live births increase from 17.1 to 23.5. In comparison, the Healthy People 2010 rate goal for congenital syphilis is 1.0 case per 100,000 live births.<sup>2,7</sup> Reasons for provider nonreporting to the health department of these identified infants reflected lack of diagnosis of the cases and/or lack of knowledge of reporting requirements, both of which would have been prevented by timely identification and investigation of the maternal positive test values by the state and county health departments. Underreporting of congenital syphilis cases has been demonstrated in other regions due to lack of provider reporting.<sup>9,17,20,21</sup> Identification of unreported cases would allow for adequate maternal/infant treatment, as well as more complete local and national surveillance, making available appropriate resource allocation based on actual morbidity.

Gaps in health department investigation of women with positive syphilis lab tests were evident in this analysis and reflect a breakdown in the timely communication and investigation of positive lab results by the state and county health departments, limited health department staff skilled in lab interpretation, and/or underutilized prioritization systems for case investigations.<sup>22</sup> The results of this study will be used to reemphasize the need for timely investigation of women with positive syphilis lab results in Arizona and to ensure appropriate

reporting and treatment of mothers and infants with syphilis via public health department and healthcare provider educational activities that emphasize the need for rapid assessment and management of women who test positive with syphilis. These results will also be used to support health policy related to prenatal syphilis testing and syphilis reporting that are deemed necessary to help reduce congenital syphilis in Arizona. As well, this evaluation identified three cases in which positive RPR results were not recorded in the STD database. A planned transition to electronic laboratory reporting will most likely improve time-to-reporting and the percentage of positive labs reported. Finally, the ADHS STDP will use this cross-match method of congenital syphilis case detection on an annual basis with particular focus on bringing to care untreated cases. Given the importance of identifying unreported and/or untreated infants with congenital syphilis, the methods presented here should be considered for use in other jurisdictions facing high or emergent congenital syphilis morbidity.

## REFERENCES

- Alexander JM, Sheffield JS, Sanchez PJ, et al. Efficacy of treatment for syphilis in pregnancy. *Obstet Gynecol* 1999; 93:5–8.
- Centers for Disease Control and Prevention. *Sexually Transmitted Disease Surveillance, 2007*. Atlanta, GA: US Department of Health and Human Services, 2008. Table 39.
- Centers for Disease Control and Prevention. *Sexually Transmitted Disease Surveillance, 2002*. Atlanta, GA: US Department of Health and Human Services, 2003.
- Centers for Disease Control and Prevention. *Sexually Transmitted Disease Surveillance, 2003*. Atlanta, GA: US Department of Health and Human Services, 2004.
- Centers for Disease Control and Prevention. *Sexually Transmitted Disease Surveillance, 2004*. Atlanta, GA: US Department of Health and Human Services, 2005.
- Centers for Disease Control and Prevention. *Sexually Transmitted Disease Surveillance, 2005*. Atlanta, GA: US Department of Health and Human Services, 2006.
- Centers for Disease Control and Prevention. *Sexually Transmitted Disease Surveillance, 2006*. Atlanta, GA: US Department of Health and Human Services, 2007.
- Arizona Administrative Code. A.A.C. R9–6–202. available at: [http://www.azsos.gov/public\\_services/Table\\_of\\_Contents.htm](http://www.azsos.gov/public_services/Table_of_Contents.htm). Accessed April 17, 2009.
- Robbins A. Congenital syphilis, New Mexico 1990–2003. *N M Epidemiol* 2005; 23:1–3.
- Centers for Disease Control and Prevention. 2006 sexually transmitted disease treatment guidelines. *Morb Mortal Wkly Rep* 2006; 55(RR-11):1–94. The form is available upon request from the Centers for Disease Control. Instructions for completion of the form and description of the form can be found at <http://www.cdc.gov/std/Program/ConSyphlnstr11-2003.pdf>. These are “The Congenital Syphilis Case Investigation and Reporting Form Instructions.” Accessed November 4, 2009.
- FORM CDC 73.126. Congenital Syphilis (CS) Case Investigation and Report. Rev 10–2003.
- Centers for Disease Control and Prevention. Congenital syphilis—United States, 2000. *Morb Mortal Wkly Rep* 2001; 50:573–577.
- Taylor MM, Mickey T, Browne K, et al. Opportunities for the prevention of congenital syphilis in Maricopa County, Arizona. *Sex Transm Dis* 2008; 35:341–343.
- 2007 Arizona STD Annual Report. Arizona Department of Health Services STD Control Program. Available at: <http://azdhs.gov/phs/oids/std/pdf/Arizona%20STD%20Annual%20Report%202007.pdf>. Accessed April 12, 2009.
- Warner L, Rochat RW, Fichtner RR, et al. Missed Opportunities for Congenital Syphilis Prevention in an Urban Southeastern Hospital. *Sex Transm Dis* 2001; 28:92–98.
- Carillo LA, Campos-Outcalt D, Coonrod DV, et al. Congenital Syphilis in Maricopa County, Arizona. *Obstet Gynecol* 2005; 105:106S.

17. Beltrami J, Berman S. Congenital syphilis: A persisting sentinel public health event. *Sex Transm Dis* 2006; 33:675–676.
18. Mobley JA, McKeown RE, Jackson KL, et al. Risk factors for congenital syphilis in South Carolina. *Am J Public Health* 1998; 88:597–602.
19. Centers for Disease Control and Prevention. Congenital syphilis—United States, 2002. *Morb Mortal Wkly Rep* 2002; 53:716–719.
20. St. Lawrence JS, Montano DE, Kasprzyk D, et al. STD screening, testing, case reporting, and clinical and partner notification practices: A national survey of US physicians. *Am J Public Health* 2002; 92:1784.
21. Centers for Disease Control and Prevention. Evaluation of congenital syphilis surveillance system—New Jersey, 1993. *Morb Mortal Wkly Rep* 1995; 44:225–227.
22. Surveillance Case Definitions. Surveillance and Data Management. Program Operations: Guidelines for STD Prevention. Centers for Disease Control and Prevention. S23–S27. Available at: [www.cdc.gov/std](http://www.cdc.gov/std).