



## Strengthening STD Prevention and Control for Health Departments

### Technical Assistance Note # 4| Congenital syphilis surveillance and case review

#### From Strategy Area I: Conduct Surveillance

#### 4. Conduct congenital syphilis (CS) surveillance

- a. To better understand CS epidemiology, conduct provider and mother follow-up and review medical records of all reported CS cases. Based on information collected, manage, analyze, and disseminate data on reported cases of CS, ensuring timely and quality capture of epidemiologic core maternal, fetal, and neonatal variables including, but not limited to: mother's age, race/ethnicity, county, stage of syphilis diagnosed during pregnancy, date(s) of 1st prenatal visit, syphilis testing (and corresponding titers), treatment(s) and delivery; HIV status of mother, substance use, clinical settings of diagnosis and care; and fetal and neonatal information such as ultrasound findings, physical and laboratory findings, and HIV status of infant at birth
- b. For applicants with **10 or more cases of congenital syphilis in the previous calendar year**: Improve methods to match vital statistics birth and mortality data with syphilis surveillance data to review syphilis testing practices among women who delivered a stillborn baby, identify missed cases of syphilis-related stillbirth, and strengthen CS case report data
- c. For applicants with **10 or more cases of congenital syphilis in the previous calendar year**: Strengthen CS morbidity and mortality case review boards at the local and/or state level to help identify causes of CS and develop interventions to address causes

### Why DSTDP included these strategies

There has been a sharp increase in the number of infants born with congenital syphilis (CS) in the United States. After a steady decline from 2008 to 2012, reported CS cases almost tripled during 2012–2017. This increase parallels a national increase in primary and secondary syphilis among women of reproductive age during the same years.

Timely identification (through screening) and treatment of pregnant women with syphilis can prevent CS. The resurgence of CS points to missed opportunities for prevention. CS surveillance monitors trends in cases over time and by geographic area, which is critical for identifying outbreaks and targeting resources. In addition, information collected as part of CS case reporting, such as data on maternal prenatal care, testing, treatment, and other potential risk factors, can assist in understanding barriers to CS prevention and suggest potential points of intervention.

For jurisdictions with a substantial burden of CS cases, enhanced activities such as matching syphilis surveillance and vital statistics data, and case review boards are useful to assess or improve completeness of case report data, gather additional information about CS cases, better describe missed opportunities for prevention, and develop appropriate interventions at the local level.

These strategies complement others in STD PCHD related to disease investigation and intervention of pregnant women, as well as the promotion of CDC-recommended STD clinical prevention services among health care providers that serve pregnant women. See **TA Notes # 7 and #12a** for more information on those strategies and ways to implement them.

## Considerations for implementation

### Collect maternal and clinical data on all reported CS cases to strengthen CS surveillance and better understand CS epidemiology

- Verify that CS cases are categorized and reported according to the most recent CSTE case definitions for confirmed CS, probable CS, and syphilitic stillbirth: <https://wwwn.cdc.gov/nndss/conditions/congenital-syphilis/case-definition/2015/>
- Collect and transmit CS case report data to CDC using the most recent (2013) version of the case report form: <https://www.cdc.gov/std/program/congenital-syphilis-form-2013.pdf>
- Assess and assure timeliness of case reporting to the local health department, state health department, and CDC; as a target, interval between report to the state health department and report to CDC should be  $\leq 8$  weeks
- Assess completeness of CS case report data and minimize incomplete or missing data fields on the CS case report form
- On a regular basis, review reported CS cases (as well as female syphilis surveillance data) to understand the populations affected and missed opportunities for prevention (e.g., lack of or late prenatal care; delay in testing or treatment; infection after initial screening test)
- Consider linking CS cases to the mother's syphilis case report record to further examine potential maternal demographic or risk behaviors associated with CS in your jurisdiction
- To go above and beyond, consider creating a system for tracking all pregnant females with syphilis that includes results from follow-up testing during pregnancy, interim and final outcomes of pregnancy, maternal and infant co-morbidities (e.g., HIV infection), and/or additional data on potential risk factors of interest. Having data on infants who do *not* meet CS case criteria may allow for additional quality assurance and other types of epidemiologic analyses.

### For applicants with 10 or more CS cases in the previous calendar year, improve methods to match surveillance and vital statistics data

- If needed, establish a memorandum of understanding or data sharing agreement with the local or state Vital Statistics and MCH Programs to share pertinent data, and ensure a secure mechanism to view or transfer data
  - Confirm whether other health department groups (i.e., perinatal HIV) may have existing data sharing agreements and consider amending current agreements to include STD matching
- Search for mothers in MCH records, birth records, and/or infant or fetal death records that match females with reported syphilis in your STD program database
  - Matching is typically performed using a combination of key variables such as mother's name, date of birth, and geographic location
  - The method used for performing a match may vary depending on the volume of female syphilis cases or the volume of birth certificates included in the match; in general, computerized matching algorithms are preferred over manual record searches
- Review matched records to identify any previously unknown/unreported infants or stillbirths born to women with positive syphilis tests (i.e., potentially missed CS or syphilitic stillbirth cases), or any cases that warrant additional follow-up or investigation
- If MCH or vital records contain additional data of interest, including locating information or prenatal care history, consider using the match to enhance CS case data and better understand the local epidemiology of CS
- The frequency of matching will depend on health department resources and the timeliness with which vital statistics data are available; annual or semi-annual matching is likely appropriate for most programs



**Matching with MCH or vital statistics data is a retrospective review that can identify potential gaps in CS surveillance and lead to improved case ascertainment and better epidemiologic data; it does not prevent CS cases, so ensure that time and resources spent on this activity are balanced appropriately with resources spent on CS prevention activities.**

## For applicants with 10 or more CS cases in the previous calendar year, strengthen CS morbidity and mortality case review boards

- Establish a multi-disciplinary review board that includes participants from within and outside of the STD Program
  - Be sure to include at least one clinician with experience diagnosing and treating syphilis
  - Selection of external participants should be based on local epidemiology and *may* include Title V and Title X partners, Medicaid, corrections, high-volume provider groups or hospitals, and agencies or CBOs working in housing, transportation, and substance abuse
  - It is preferable to have a fixed set of Board members—both internal and external—that attend these meeting regularly
- Develop a structure to aid in the case review process. Suggested tools include a case abstraction form, a maternal interview form, and/or an after-action form that summarizes Board recommendations and suggested follow-up
- Determine meeting frequency based on CS morbidity; quarterly meetings are appropriate for most jurisdictions, but monthly meetings may be preferable in jurisdictions with very high CS morbidity
- Review *all* cases of CS, not only those cases that result in stillbirth or early infant death
- Consider integrating a CS morbidity and mortality review board with other review boards that may already be in existence. Some jurisdictions have high-functioning Fetal and Infant Mortality Review Boards that may be able to take on CS review—as a group or in sub-committee. Other jurisdictions already have review boards in place for infants exposed to HIV.



**The aim of the CS Review Board should be to identify actions that the local health department can facilitate or take to address the underlying causes of CS—some of which may be attributable to individual actions and some of which may be attributable to entire systems in need of repair.**

## Other resources

- CSTE surveillance case definitions for CS and syphilitic stillbirths: <https://www.cdc.gov/nndss/conditions/congenital-syphilis/case-definition/2015/>
- Most recent (2013) CS case report form: <https://www.cdc.gov/std/program/congenital-syphilis-form-2013.pdf>
- CDC STD Treatment Guidelines for management of CS: <https://www.cdc.gov/std/tg2015/congenital.htm>
- References for matching vital statistics to STD data:
  - Winscott, M, Taylor, MM, Kenney K. Identifying unreported and undiagnosed cases of congenital syphilis in Arizona using live birth and fetal death registries. *Sex Transm Dis*. 2010 Apr;37(4):244-7.
  - Biswas HH, Chew Ng RA, Murray EL, Chow JM, Stoltey JE, Watt JP, Bauer HM. Characteristics associated with delivery of an infant with congenital syphilis and missed opportunities for prevention - California, 2012-2014. *Sex Transm Dis*. 2018 Jul;45(7):435-441.
  - Newman LM, Samuel MC, Stenger MR, Gerber TM, Macomber K, Stover JA, Wise W. Practical considerations for matching STD and HIV surveillance data with data from other sources. *Public Health Reports*. 2009 Nov;124(2\_suppl):7-17.
  - Drobnik A, Pinchoff J, Bushnell G, Ly S, Yuan J, Varma JK, Fuld J. Matching HIV, tuberculosis, viral hepatitis, and sexually transmitted diseases surveillance data, 2000-2010: Identification of infectious

disease syndemics in New York City. *Journal of Public Health Management and Practice*. 2014 Sep 1;20(5):506-12.

- Resources for conducting Case Review Boards using the FIMR methodology (adapted for HIV contexts but helpful for planning CS-related reviews):
  - <http://www.fimrhiv.org/>
  - Rahman, M, Hoover, A, Johnson, C, Peterman, T. Preventing congenital syphilis—Opportunities identified by syphilis case review boards. *Sex Transm Dis*. 2018. (epub ahead of print)

For more information or feedback on this document, contact your DSTDP Prevention Specialist or email [STD\\_PCHD@cdc.gov](mailto:STD_PCHD@cdc.gov). CDC's Division of STD Prevention, Program Development and Quality Improvement Branch, developed this document for recipients of PS19-1901 STD PCHD to provide additional clarification of strategies outlined in that NOFO and to support program implementation. The content here does not represent additional NOFO requirements nor official CDC recommendations. Issue date: April 2019