

## Congenital Malformations Rates: Beginning 1992

### Overview

The Congenital Malformations Registry (CMR) of the New York State Department of Health is a repository for case reports on children who are born or reside in New York State. The CMR has been in existence since 1982 with 1983 the first full year of data. The CMR covers the entire state of New York, including New York City. Reporting of children with major birth defects to the CMR is mandated by law. The CMR was established as part of the Environmental Disease Surveillance Program in 1982, by enactment of [Part 22](#) of the New York State Sanitary Code. [Part 22](#) stipulates that every physician and hospital in attendance on an individual diagnosed within two years of birth as having one or more congenital anomalies shall file a supplementary report with the State Commissioner of Health. A congenital anomaly is defined as any structural, functional or biochemical abnormality determined genetically or induced during gestation and not due to birthing events.

By law, data collected by the CMR can be used only for surveillance and to facilitate epidemiologic research into the prevention of environmental diseases, as prescribed by Public Health Law 206(1J). Confidentiality of all data reported to the Registry is strictly maintained by Department of Health staff and rigorously safeguarded by Section 206(1J), which specifically prohibits the release of personal identifiers. Families of cases are never contacted without prior consent of the Department of Health's Institutional Review Board. The CMR was awarded the National Birth Defects Prevention Network's (NBDPN) "State Service/State Leadership Award" in 2007. This annual award is given to a state program or agency to honor outstanding contributions by a state registry in the development or expansion of birth defects surveillance. The CMR was recognized for its web-based system for case reporting, data management and communication.

The CMR receives reports on over 12,000 children each year. Beginning in 1992, the CMR began to use the British Pediatric Association (BPA) coding, which allows for greater specificity than ICD-9 coding. CMR staff performs the coding based on narrative descriptions of the birth defects reported by hospitals. We believe that the required reporting of the narrative diagnosis contributes appreciably to the accuracy of the CMR. Surveillance includes on-going efforts to take advantage of changes in resources and technologies. The CMR has been used for almost 100 publications.

From the beginning, the New York State CMR has actively sought means to monitor data quality and completeness. In 2002, a match of CMR reports with reports from the active case ascertainment of the NBDPS found that the CMR ascertained 89% of all reportable cases (C. Druschel unpublished data, 2002). Since that time we have initiated a number of data quality measures to further improve completeness of reporting. **The CMR has continued to improve case ascertainment and now has four major approaches to optimize data quality:** 1) matching to hospital discharge data, the Statewide Planning and Research Cooperative System (SPARCS) dataset for completeness; 2) a web-based reporting system for timeliness and completeness; 3) both on-site and off-site hospital audits for completeness and accuracy; and 4)

mandated reporting by licensed clinical laboratories to identify cases and as a source of genetic information.

#### *1) SPARCS Audits*

For the SPARCS audit, children under age 2 years and diagnosed with reportable birth defects are selected from SPARCS files of all reporting hospitals and matched to the CMR database for the same birth year period. As of 2010, the SPARCS database includes emergency room visits and outpatient surgeries. Unmatched reports from the SPARCS hospital discharge files are sent to the hospital, requesting submission of the missed reports (Wang et al., 2005). Less than 10% of cases in the CMR result from the SPARCS audit, demonstrating good hospital compliance. Auditing hospitals by CMR staff ensures registry completeness and sends a message to reporting hospitals that both the quality and the quantity of their reports are closely monitored.

#### *2) HCS Reporting*

The NYSDOH Health Commerce System (HCS), formerly the Health Provider Network (HPN) is a secure system for electronically collecting and distributing health-related data (Wang et al., 2007a). It has been used for reporting communicable diseases. After pilot testing with two hospitals in 2001, the system was phased in for reporting in 2003. **This innovative system enables CMR staff to review and perform quality assurance on every report submitted and to query hospitals immediately about submitted reports.** CMR staff can review hospital reporting and immediately contact hospitals who are late in reporting. A study found that the implementation of the HCS system has resulted in more timely submission of cases and promoted effective communication between the CMR and reporting hospitals (Wang et al., 2007a). There was a nearly 50% reduction in median days used for reporting (Wang et al., 2007b). For 2006, the mean time from hospital discharge to reporting to the HCS was 60 days, with 50% of reports coming in by 30 days. Pat Steen monitors reporting and follows up with medical records personnel in hospitals that fall behind in reporting. We have also initiated a policy of sending letters to hospital administrators commending hospital medical records personnel who are especially conscientious and timely in reporting to the CMR.

#### *3) On-site Hospital Audits*

On-site hospital audits were piloted in 2002 and implemented in 2003. CMR staff request a discharge summary for all children 2 years of age and younger for a specific discharge period, usually one year. The list includes all children discharged in that year, not just those with a birth defect code. This is done so that reportable conditions that may have been miscoded can be identified. CMR staff review the discharge list, comparing it to the list of children who have already been reported to the CMR. CMR staff then create a list of reported, not reported, and partially reported cases. At the completion of the review, the facility will be asked to report any missed cases. A written summary of the audit findings is sent to the Director of medical records including comments that may indicate what chronic reporting problems were evident. Since 2003, all of the major reporting hospitals in NYS have had an “in-house” audit including those in the study areas. We have observed an error rate of about 1%.

#### *4) Off-site Hospital Audits*

The CMR also uses hospital discharge summaries (most of which are electronic) as an additional source of case finding. These summaries list all children discharged from the hospital, include a narrative (SPARCS has only ICD-9 codes) and are complete. Summaries are reviewed for possible missing cases. As more hospitals move to comprehensive electronic medical records systems, these electronic systems may facilitate both case finding and confirmation of diagnoses.

The CMR will continue to review procedures and develop new methods to ensure accuracy and completeness of the CMR.

5) *Electronic Clinical Laboratory Reporting System (ECLRS)*

The NYSDOH implemented electronic reporting for laboratories across the state including those doing genetic testing in 2001. CMR staff have access to the Electronic Clinical Laboratory Reporting System (ECLRS) via the HCS. Reports from clinical laboratories are a source of additional genetic information helpful in determining case eligibility.