



Monthly Newsletter From the International Clearinghouse November 2013 (issue 2013-11)

What's going on regarding birth defects

Themed Issue on Birth Defects Registry Methods, Spring 2014, Journal of Registry Management. The National Birth Defects Prevention Network (NBDPN) is continuing its arrangement with the Journal of Registry Management (JRM) to provide a themed issue on birth defects surveillance, with papers focusing on birth defects program methods, approaches to assuring/evaluating data quality and completeness, and innovative approaches to improving the science and practice of birth defects surveillance. **Due date for submission: January 15, 2014.** See also www.nbdpn.org/jrm_call_for_manuscripts.php

The **National Registry of Congenital Anomalies in Argentina, RENAC** published an article on the characteristics and operation of the registry and on the prevalence of 56 specific anomalies. An English translation is available (free access) at www.sap.org.ar/docs/publicaciones/archivosarg/2013/v111n6a05e.pdf

A study based on data from **Texas Birth Defects Registry** showed that greater distance from birth center to cardiac surgery center was associated with increased neonatal mortality of infants with hypoplastic left heart syndrome (HLHS), with most of this mortality being pre-surgical. Efforts to improve prenatal diagnosis of HLHS and subsequent delivery near a large volume CSC may significantly improve outcome of infants with HLHS. Reference: Shaine A. Morris, Mary K. Ethen, Daniel J. Penny, Mark A. Canfield, Charles G. Minard, David E. Fixler, and Wendy N. Nembhard. Prenatal Diagnosis, Birth Location, Surgical Center, and Neonatal Mortality in Infants with Hypoplastic Left Heart Syndrome. *Circulation*. 2013 (available online ahead of print as doi:10.1161/CIRCULATIONAHA.113.003711)

The **Northern Netherlands** program recently published a study in the *European Journal of Epidemiology* in which they report on **an increased risk of oral clefts**, in particular cleft lip/alveolus, in association with **periconceptional folic acid use**. In this study data from both the birth defects registry and the national clefts register were combined and classified according to the standard classification and according to timing and underlying developmental mechanisms. The article can be found at <http://link.springer.com/article/10.1007/s10654-013-9849-0>

News from the Headquarter and Executive Committee

Pre-conference Educational Workshop on Birth Defects Surveillance and Prevention, November 9-10, 2013 Cebu, Philippines. This 1 ½ day workshop, organized by the ICBD with support from the CDC, took place in conjunction with the 6th International Conference on Birth Defects and Developmental Disabilities in the Developing World. Over 80 participants, mainly from South East Asia and the Philippines but also others, and nearly all from developing countries, made it to Cebu, typhoon notwithstanding, for a packed schedule of lectures and discussion. In addition, participants were provided with tools to continue promoting birth defect surveillance and prevention when they return back home. Thanks to the faculty— Cindy Moore from the CDC, and Lorenzo Botto and Pierpaolo Mastroiacovo from the Clearinghouse - for their willingness to travel and lead the workshop, and to Simonetta Zezza (ICBD) for the incredible amount of organizational work that was required.

Update on the upcoming Annual Meeting

In order help share information about ongoing activities and to save time during the Business Meeting, **all program leaders are kindly requested to prepare and send to ICBD as soon as possible a short report of half a page on the activities of your surveillance program.** The reports will be published before the annual meeting on the restricted part of the website. During the meeting members can highlight or clarify the most important issues (max 2 minutes for each program). In the coming days extra documents and information for the AM will be distributed by email and placed on restricted area of the website.

Upcoming deadlines

20 November, 2013: Data for the 4th quarter 2012, to be published in the **Quarterly Report**.

Would you like to contribute with any news from your program for next Monthly Newsletter?

Please send contributions, comments or questions to centre@icbdsr.org