

Monthly Newsletter From the International Clearinghouse October2013 (issue 2013-10)

What's going on regarding birth defects

Collaborating with consumers to promote acceptable and open statutory notification of birth defects. The recent paper by Bower et al from Western Australia (*J Registry Manag [2013; 40(1):9-13]*) describes the successful engagement of community members, leading to an open discussion and productive collaboration, and culminating in achieving statutory notification. In addition, the ongoing substantive partnership of consumers and community members bodes well for the future. PDF available on request at centre@icbdsr.org

Birth Defects Program Roles in Screening for Critical Congenital Heart Defects (CCHD). Screening for CCHD is a growing concern in many countries, and birth defects program are called to help assess and improve this novel newborn screening method. A recent publication from the United States relates the experience of several such efforts. Although focused on the realities of the United States, the discussion and issues presented can be of considerable interest to many of us who are or will soon address these same issues. (Link to the PDF: www.amchp.org/programsandtopics/CHILD-HEALTH/projects/newborn-screening/Documents/AMCHP Screening for CCHD Issue Brief FINAL-Oct2013.pdf)

Estimating the potential impact of folic acid fortification of corn flour on preventing neural tube defects. The authors of this study from the CDC (http://onlinelibrary.wiley.com/doi/10.1002/bdra.23158/abstract) used modeling to estimate the additional benefit of corn flour fortification among US Hispanics in particular, and may be of interest to those of us working in areas in which corn flour is a common staple (some fortification programs currently do not include corn flour).

News from the Headquarter and Executive Committee

40th ICBDSR Annual Meeting(Costa Rica, December 3-6, 2013): Presentations Now Selected. The Annual Meeting Committee (Marian Bakker, Eva Bermejo, Adriana Benavides, Mark Canfield and Gioacchino Scarano) reviewed the abstracts submitted by the deadline. Notification of acceptance has been sent to the Authors of 12 posters and 24 oral presentations. The presentations will be arranged into five Scientific Sessions:

Folic acid, vitamins and diet; Risk Factors; Congenital Heart defects; Genetics; Surveillance

Pre-conference Educational Workshop on Birth Defects Surveillance, November 9-10, 2013, Cebu (Philippines). At this time, >85 participants are expected, with approximately 30 from 11 countries in the South East Asia and Western Pacific Regions (SEAR and WPR) and 55 from the Philippines. Faculty includes Lorenzo Botto and Pierpaolo Mastroiacovo from ICBDSR (at no cost to the Clearinghouse), and Coleen Boyle and Cynthia Moore from CDC. Organized in conjunction with the 6th International Conference on Birth Defects and Disabilities in the Developing World (www.ICBD2013.com), the workshop promotes a major goal of the Clearinghouse: international surveillance of birth defects, with emphasis on new programs and developing countries.

Upcoming deadlines

- 15 November, 2013:registration form for the Annual Meeting
- 15 November, 2013:hotel reservation for Annual Meeting. For details see ICBDSR website.
- 20 November, 2013:Data for the4th quarter 2012, to be published in the Quarterly Report.