



Monthly Newsletter From the International Clearinghouse January 2013 (issue 2013-1)

What's going on regarding birth defects

- **January 6-12th is the National Folic Acid Awareness Week** in USA. For further details, visit the National Council on Folic Acid (NCFA) website: http://www.folicacidinfo.org/pages/folicacid_info.php
- **Food & Nutrition Bulletin** December 2012 issue (Vol 33, Suppl 3) is all about food fortification. Link to the full text: <http://www.ingentaconnect.com/content/nsinf/fnb/2012/00000033/a00304s3>
- **2013 Birth Defects Prevention Month: "Birth defects are common, costly, and critical"**. This is the theme chosen for the 2013 Birth Defects Prevention Month. The NBDPN Parent Advisory Group developed a Birth Defects Awareness Campaign, launched on 2 January 2013. A Public Service Announcement (PSA) video and a toolkit are available, free of charge, in both English and Spanish. However, you may translate both the PSA and toolkit materials into any language. Materials and packets are available to all Clearinghouse members and others who may want to use them in their own countries. PSA video: <http://www.youtube.com/NBDPN>; Materials in English and Spanish: <http://www.nbdpn.org/bdpm2013.php>; Entire packet: <http://www.nbdpn.org/docs/2013BDPMPacket.pdf>
- The Pediatrics journal has published a new study: "Trends in survival among children with Down syndrome in 10 regions of the United States. Thanks to Csaba Siffel for providing this link: <http://www.cdc.gov/ncbddd/features/keyfindings-ds-survival.html>. This is the largest known population-based study on survival of people with Down syndrome (DS). Survival has increased over the time, but the study identifies certain factors, including low birth weight and the presence of a major heart defect that might increase the risk for death among babies born with DS. Increasing awareness of the risks associated with these factors can help health care providers better address medical needs and promote health among people with DS.
- **Journal of Registry Management (JRM): Themed Issue on Birth Defects Registry Methods, Spring 2013**
Call for manuscripts for a themed issue on birth defects surveillance, with papers focusing on the following areas:
 - Use of surveillance data to support public health program assessment, design, and evaluation
 - Cluster investigations
 - Statistical techniques, role and/or use of GIS, or meta-analyses
 - Quality assurance: general protocols, re-abstraction techniques, assessment methods, and/or evaluation
 - Methods for presentation and dissemination of birth defects data
 - Program methodology: role of advisory committees, model legislation, methods for planning and evaluation, and/or prenatal and stillbirth surveillanceFull information at http://www.nbdpn.org/jrm_call_for_manuscripts.php. **Due Date for Submission: Monday, January 28, 2013**

News from the Headquarter and Executive Committee

- **2013 Training Program on Surveillance and Prevention of Birth Defects and Preterm Births** (Geneva, May 27-31, 2013): the deadline for application is January 31, 2013. Please, spread this link to possible interested colleagues: www.icbdsr.org/page.asp?n=Training_Program
- **ICBDSR 2012 Annual Report**: in preparation, with 2010 data. In order to have the most up-to-date and correct information about your program, would you please:
 - **Update the description of your Program**. Please look at your Program's description as published in the most recent AR. You can download the AR 2011 at: <http://www.icbdsr.org/filebank/documents/ar2005/Report2011.pdf>
 - **Send a list of papers** by you or your collaborators, published in 2011-2012, to be included in the section "Publications by ICBDSR Members" of the Annual ReportThe deadline for receiving the requested information is **February 28, 2013**
- **The Executive Committee** will have its next meeting at the Clearinghouse Headquarter in Rome on Jan 31 and Feb 1, 2013.
- **2013 ICBDSR Annual Meeting**: it will take place in San José, Costa Rica, in the first week of December 2013. Further details to follow in the ICBDSR website.

Upcoming deadlines

- **February 20, 2013**: Data for the **1st quarter 2012**, to be published in the **Quarterly Report/Krystalos**.
- **February 28, 2013**: update of Program description and list of papers published in 2011-2012.

*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*