



## Monthly Newsletter From the International Clearinghouse

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### What's going on regarding birth defects

The National Birth Defects Prevention Network's Education and Outreach Committee has just presented the **2014 Birth Defects Prevention Month Packet**, available at <http://www.nbdpn.org/bdpm2014.php>. The entire packet can be downloaded at [http://www.nbdpn.org/docs/2014\\_BDPM\\_Packet18Nov2013.pdf](http://www.nbdpn.org/docs/2014_BDPM_Packet18Nov2013.pdf). NBDPN's goal for 2014 is to continue to increase awareness that birth defects are "Common, Costly and Critical" and to offer actionable steps that can be taken by professionals, community groups, and the public to prevent birth defects. Some of the new resources include sample letters to health care providers, a factsheet for policy makers, resources for grandparents of children with birth defects, and tailored materials for local health department. These resources can be shared with colleagues, policy makers, families, and others during Birth Defects Prevention Month and throughout the year.

An update on genetic testing has been published in the December issue of the *American Journal of Medical Genetics part A* (<http://onlinelibrary.wiley.com/doi/10.1002/ajmg.a.36349/pdf>), written by D. Levenson, who underlined **NGS (Next-Generation Sequencing)** may reduce cost and wait time for some genetic diagnoses, but also that clinical evaluation remains crucial.

Metcalfe et al have just published a paper in *Birth Defects Research Part A: Clinical and Molecular Teratology* (available on early view: doi: 10.1002/bdra.23206), on the validation of congenital anomaly (CA) coding in Canada's administrative databases compared with the data from the Alberta Congenital Anomalies Surveillance System as the reference standard. They conclude that the validity of CA coding in administrative databases compared with a CA registry varies by database used and by CA studied. This has important implications for national surveillance efforts, and condition-specific validity should be assessed locally before use of these data sources for research or planning purposes.

### News from the Headquarter and Executive Committee

- The **40<sup>th</sup> Annual Meeting of ICBDSP** took place in San José (Costa Rica), hosted by Dr. Adriana Benavides and her team from INCIENSA-CREC. Eighteen ICBDSP programs were represented there, and a total of 38 attendees participated in the meeting. The J. David Erickson Lecture was awarded to Prof. José F. Cordero, and the **Alessandra Lisi Award Winner** was Tanya Bedard, from Canada. Drs. Manuel Saborío and María de la Paz Barboza, from Costa Rica, were the Keynote Lecturers. There were 23 oral and 9 poster presentations, with 5 introductory updates on the main themes of the meeting: Surveillance, Risk factors, Congenital heart defects, Genetics, and Folic acid, vitamins and diet.
- **41<sup>th</sup> Annual Meeting of ICBDSP**: It will be hosted by Anukka Ritvanen, from Finland, and will take place in Helsinki on September 13-17, 2014. Take note in your agenda! More information will be distributed and uploaded to the website.
- The **2013 ICBDSP Distinguished Service Award** honored Dr. Eduardo E. Castilla, from ECLAMC, for longstanding service to the Clearinghouse, as well as excellence, and leadership.
- Two **new ICBDSP members**: The applications by the Arkansas Reproductive Health Monitoring System (ARHMS), and the Iowa Registry for Congenital and Inherited Disorders (IRCID), were unanimously accepted at the Business Meeting of the Clearinghouse.
- **New Executive Committee's officers**: Chair: Marcia L. Feldkamp (from UBDN - Utah, USA); Vice-Chair: Eva Bermejo-Sánchez (ECEMC-Spain); Secretary/Treasurer: Mark A. Canfield (TBDES-Texas, USA).

### Upcoming deadlines

- **January 15, 2014**: Due date for submission of papers for the **Themed Issue on Birth Defects Registry Methods, Spring 2014, Journal of Registry Management**, according to the arrangement with the National Birth Defects Prevention Network (NBDPN). See also [www.nbdpn.org/jrm\\_call\\_for\\_manuscripts.php](http://www.nbdpn.org/jrm_call_for_manuscripts.php)
- **February 20, 2014**: Data for the **1st quarter 2013**, to be published in the **Quarterly Report/Krystalos**.

### Still on time

- If not yet done, **you are still on time to send the Short Report** (half a page) of activity of your program in 2013, to be shared with all Clearinghouse members in the restricted area of the website. Address it to [centre@icbdsr.org](mailto:centre@icbdsr.org). Thanks to all of you who already did it!

**Seasons greetings to all! We hope the new year brings you happiness, health, and prosperity.**

*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](mailto:centre@icbdsr.org)*