

# Monthly Newsletter From the International Clearinghouse

December 2014 Issue 2014 - 12

## **What's Going on Regarding Birth Defects**

The "World Birth Defects Day" will be celebrated on March 3, 2015. Eleven outstanding organizations involved in the field of Birth Defects and/or in the field of Maternal and Child Health agreed to promote this Day. In early November an **official letter** to announce the "World Birth Defects Day" had been disseminated among ICBDSR members. **Other tools for informing media** were also distributed: a letter to media, short messages to disseminate, Twitter messages to launch.

Please remember that magazines need 2-3 months to plan articles for a March 2015 issue, so we recommend contacting them as soon as possible (December 15 at latest, to be sure). Use the deadline of December 15 also for making plans and contacts with all the other media. The logo for the day and a composite logo of the worldwide promoting organizations are still in progress.

Remember that your <u>individual</u> contribution to disseminate this worldwide action is crucial and can be carried out only by you. Your contribution together with those of others will compose this global action.

### **News from Programs**

• Brian Lowry et al have just published a paper in *Cleft Palate-Craniofacial Journal* (2014 Nov;51(6):e113-21. doi: 10.1597/13-340) with data from the Canada Alberta Program ACASS. Rates for cleft lip with or without cleft palate and cleft palate only have been very stable over the 33-year period (1980-2011). They concluded that it is unclear whether folic acid fortification has had any impact in Alberta. Because of copyright restrictions imposed by this journal, ICBDSR members can obtain it through their institutional licenses, or download it from the Journal 6 months after publication.

#### **News from the Headquarters and Executive Committee**

- The Annual Meeting planning committee for 2015 has been established. Members are: Miriam Gatt and Anke Rissmann, together with Simonetta Zezza and Pierpaolo Mastroiacovo as local organizers, and Marcia Feldkamp, Eva Bermejo, and Mark Canfield as Executive Committee members. One of the duties of the committee is to discuss and decide the possible themes for the Scientific Sessions, following the several suggestions obtained from the evaluation forms completed by attendees at the Helsinki meeting. The committee will also evaluate, select and review the abstracts for the Scientific Sessions.
- From December 1<sup>st</sup>, 2014, the telephone number of the ICBDSR Centre will also **act as fax: +39 06 3701905.** Please disregard the other number (+39 06 3701904 is no longer in use)

### **Progress of collaborative projects**

- The project on prenatal diagnosis and outcomes of **congenital heart defects** is in progress, as it was explained by Lorenzo D. Botto in Helsinki, during our Annual Meeting.
- The collaborative project on **hypospadias** has started. A questionnaire about the participation in this study has been distributed among members, and 27 programs sent back their response. Some of them already provided updated data, some others will provide data by next deadlines.
- You will soon hear more about the survival study/project(s) for selected birth defects.

SAVE THE DATE: 10-13 September 2015, 42<sup>nd</sup> Annual ICBDSR Meeting in Spoleto, Italy at Albornoz Palace Hotel http://www.albornozpalace.com/eng/index.html

#### **Passed deadlines**

- November 15: questionnaire on participation in the collaborative project on hypospadias (see above).
- **November 20**: data for the 4<sup>th</sup> Quarter 2013 not all the participating programs provided quarterly data a reminder has been sent just after the deadline
- **November 30:** annual data (2012, or the most recent available year), for the Annual Report 2014 not all the participating programs provided Annual Data a reminder will be sent by the next few days

#### **Upcoming deadlines**

- December 31: last call for payment of 2014 dues from missing programs (this can affect the voting right)
- February 20: data for the 1st Quarter 2014



