



## Monthly Newsletter From the International Clearinghouse

January 2015

Issue 2015-01

### What's Going on Regarding Birth Defects

January is **National Birth Defects Prevention Month** in the United States. The theme this year is "Making Healthy Choices to Prevent Birth Defects: Make a **PACT** for Prevention". This year all pregnant women and those who may become pregnant are encouraged to: **Plan ahead - Avoid harmful substances - Choose a healthy lifestyle - Talk to your healthcare provider**. The full packet of materials can be found at <http://www.nbdpn.org/bdpm2015.php> (English, some documents in Spanish). Some of the activities and news about the National Birth Defects Prevention Month:

- **Special web features:** a series of web features will be posted on the CDC website this month. The first one highlights the importance of consuming 400 micrograms of folic acid daily before and during pregnancy to reduce the risk of neural tube defects: <http://www.cdc.gov/features/folicacidbenefits/>
- During the month of January, a fact each day will be shared on **Twitter**. Each fact will be marked by the hashtag: #1in33 (a reference to the prevalence of birth defects).
- New articles in upcoming issues of CDC's **Morbidity and Mortality Weekly Report**. Check <http://www.cdc.gov/mmwr/> each week this month for new birth defects-related research findings.
- **CDC Public Health Grand Rounds:** at 1pm EST on January 20, 2015 you can join the CDC's live webcast titled "Understanding the Causes of Major Birth Defects: Steps to Prevention." Experts in birth defects research will present an overview of current and historical efforts to understand the causes of major birth defects. They will also discuss the challenges in turning research findings into effective prevention. For more information on the upcoming session, please visit <http://www.cdc.gov/cdcgrandrounds/>. Dr. Marcia Feldkamp, current Chair of ICBDSP, along with Dr. Jennita Reefhuis, Dr. Allen Mitchell, and Dr. Suzanne Gilboa are presenting. This webcast should be taped for later online viewing if needed.
- A featured **blog by NCBDDD Director**, Dr. Coleen Boyle, is posted on <http://www.hhs.gov/blog/2015/01/05/recognizing-young-children-living-birth-defects.html>.

"**World Birth Defects Day**" will be observed on March 3, 2015, and hopefully every year thereafter. The final materials about the WBDD have been distributed among Clearinghouse members: Updated letter to media and letter to contact parent organizations; two logos for the day; and an Excel spreadsheet to keep track of dissemination action(s) and achievements obtained. Please, contact [centre@icbdsr.org](mailto:centre@icbdsr.org) if you need to receive a copy of these documents or if you have any questions. Further information will be posted in the next weeks and will be available in ICBDSP's website.

**Please remember that your individual 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 the Headquarters and Executive Committee

- An "**Intermediate Congenital Anomalies Surveillance Workshop**" will take place in Arusha, Tanzania, from March 2 to 6, 2015. The Workshop is conducted in collaboration with the World Health Organization, the International Federation for Spina Bifida and Hydrocephalus (IFSBH), and the U.S. Centers for Disease Control and Prevention (CDC). The funding agencies (IFSBH and CDC) extended invitations to key individuals in countries where birth defects surveillance is being developed or implemented. Lorenzo Botto and Pierpaolo Mastroiacovo will attend the Workshop as members of the Faculty, in representation of the Clearinghouse. Boris Groisman from RENAC, Argentina, is the person in charge for the online pre-course arrangement.
- The next **Executive Committee Meeting** will take place in Rome, at ICBDSP Headquarter, from March 16 to 18, 2015.

### Progress of collaborative projects

- The collaborative project on **hypospadias** is in progress. Among the 28 participants programs, only few have not yet provided updated data. As soon as all data will be collected, a Principal Investigator will be identified among those who expressed their willing to be part of the Analysis and Writing Working Group
- You will soon hear more about the "**Prenatal diagnosis and congenital heart defects**" and about the "**Survival study/project(s) for selected birth defects**."

### Upcoming deadlines

- **February 20:** data for the 1<sup>st</sup> Quarter 2014

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