

Monthly Newsletter From the International Clearinghouse

October 2015

Issue 2015-10

What's Going on Regarding Birth Defects

- The first LATin AMerican Training Program (LATAM/TP) will be held in Costa Rica, from November 23th to 27th 2015. A total of 16 countries (11 from South America and 6 from Central America and Caribe) will be participating. The LATAM/TP objective is to enable Latin American countries to develop / improve their own surveillance programs and thus become part of the Clearinghouse. For many of these countries it is very difficult to send people to trainings outside Latin America for two main reasons: costs and language barrier. LATAM / TP pre-course has used the same Moodle platform as the ICBDSR Trainings. The organizers developed their own classes based on the Geneva Training Program materials, translating in Spanish the lessons/presentations and complementing the materials with their own knowledge and examples in Latin America. The LATAM Faculty members are:
 - ✓ Diana Valencia and Alina Flores U.S. Centers for Disease Control and Prevention (CDC)
 - ✓ Pablo Duran Organización Panamericana de la Salud (OPS)/OMS
 - 🖌 Boris Groisman, Maria Paz Bidondo, Pablo Barbero, Rosa Liascovich, Juan Gili RENAC, Argentina
 - ✓ Ignacio Zarante and Paula Hurtado Universidad Javeriana, Bogota, Colombia
 - ✓ Adriana Benavides, María de la Paz Barboza and Jorge Sequeira CREC, Costa Rica
- November 17 is World Prematurity Day. Add you voice to raise awareness! Join the Thunderclap campaign at https://www.thunderclap.it/projects/31695-world-prematurity-day?locale=en
- The *National Birth Defects Prevention Network (NBDPN)* will be holding its *2015 Annual Meeting* on October 19-21, at the Key Bridge Marriott Hotel in Arlington, VA. Further information at http://www.nbdpn.org/2015 annual meeting.php
- The **9th International Neural Tube Defects Conference** will be held in Austin, Texas, October 26 (opening reception 5-7pm) October 29. Additional information about the meeting at http://ntdconference.com

News from Members

Reports on the activities of membersin the last year are available in the restricted area of the website, and you are kindly invited to send yours to <u>centre@icbdsr.org</u> if not already done.

News from the Headquarters and Executive Committee

- ICBDSR Mortality Study: study protocol and sample spreadsheet for reporting data has been distributed among ICBDSR members. Responses for participation in any mortality study and willingness to be Principal Investigator are due by October 31, 2015
- The **43rd Annual Meeting** of the Clearinghouse will be held in Magdeburg (Germany), from September 18th-22nd, 2016. (one week later than the initially planned dates, as presented in Spoleto).
- Pierpaolo Mastroiacovo, ICBDSR Centre Director, has been invited to give a presentation on "Birth Defects Prevention" at the **Dysmelia Expert Forum Conference**, held in Stockholm (Sweden) on October 8-11, 2015. The Conference is promoted by EDRIC (European Dysmelia Reference Information Centre), one of the founding organizations of the World Birth Defects Day. The three day event includes a day for experts by themselves, a second day with experts and EDRIC members together, and a third day for those personally affected by limb difference to exchange ideas and information.
- We welcome a **new affiliate member** in the Clearinghouse community: Dr. José Fernando Arena, Medical Officer at Carter Consulting, Inc., National Center on Birth Defects and Developmental Disabilities, U.S. Centers for Disease Control and Prevention (CDC). Dr Arena is a Medical Geneticist, currently working as a clinical review consultant at the Birth Defects Epidemiology and Surveillance Branch, Texas Department of State Health Services.

New resources are available in the members' area of the ICBDSR website:

- Interesting Lectures: the first lecture published in this section is the "Dave Erickson Lecture", presented at the ICBDSR Annual Meeting from RJ Berry: "Masking and other folic acid tales". Further interesting lectures will follow.
- **PEACE** (<u>Population Estimate of Attributable Fraction of Congenital Conditions Everywhere</u>): a tool to estimate the Population Attributable Fraction of some common adverse pregnancy-related outcomes for selected risk factors. Please, use the Worksheet that you can download from the website, and let us know your comments. Thanks.
- **PreSurv Suite:** an open source, free, and adaptable software to create the database of birth defects detected in your surveillance program and a set of tools for coding.