



Monthly Newsletter

From the International Clearinghouse

August 2013 (issue 2013-8)

What's going on regarding birth defects

Member programs have been busy in the last few months. Here are some recent papers of potential interest to many of us.

- **Strategies to achieve sustainability and quality** in birth defects registries. In this article, Boris Groisman and collaborators from Argentina (RENAC) present their experience in what activities improve and sustain quality, including training, research projects, ongoing feedback, providing clinical expertise and discussion forums. Reference: Groisman et al, J Registry Manag. 2013 Spring; 40(1):29-31 (PMID 23778694).
- **Current Estimate of Down Syndrome Population Prevalence** in the United States This paper provides an example of an interesting method to estimate prevalence (the number of affected people of all ages living in a population), using a life-table approach that includes the proportion of deaths age. As such, it could be used in many countries where these statistics are available. Reference: Presson et al, J Pediatr. 2013 Jul 22 (PMID: 23885965).

Also note **the upcoming 6th International Conference on Birth Defects and Disabilities in the Developing World**, November 10-13, 2013 – Cebu (Philippines). Visit <http://www.ICBD2013.com> for additional details. The deadline for registration is August 31, 2013. Before the conference, there will be the following workshop, co-organized by ICBD:

- **Pre-conference Educational Workshop on Birth Defects Surveillance**, November 9-10, 2013, Cebu (Philippines). The Workshop is organized by ICBD-Headquarter Centre of the Clearinghouse, jointly with US Centers for Disease Control and Prevention and the Organizing Committee of the 6th International Conference on Birth Defects and Disabilities in the Developing World. The Workshop is aimed at medical and public health professionals committed to birth defects surveillance and prevention. Pre-registration form and full announcement are available at www.icbdsr.org. Applications are due by 15 September 2013.

News from the Headquarter and Executive Committee

- **31 August 2013** – deadline for **abstract submission** to the 40th ICBDSDR Annual Meeting. Suggested topics include causes and mechanisms of birth defects, genomics and epigenetics of birth defects, and use of surveillance data in outcomes research and cluster management. For more information see the ICBDSDR website.
- **15 September 2013** – **important deadline for data submission** for Annual Report (2011 or most recent data): this call for data is crucial in order to keep pace with the planned yearly publication of the Annual Report.
- **Preparatory work on Genomics and Birth Defects** is continuing. Many thanks to all who have responded to the survey and to Osvaldo Mutchinick and Gioacchino Scarano for leading this effort. The survey responses are being analyzed, so expect a follow up communication and next steps from Osvaldo and Gioacchino in the near future.

Important Upcoming deadlines

- **20 August 2013**: Data for the **3rd quarter 2012**, to be published in the **Quarterly Report**.
- **31 August 2013**: submission of abstracts for the 2013 Annual Meeting
- **15 September 2013**: submission of data relative to **2011 or most recent year available**, for publication in the Annual Report 2013.
- **15 November, 2013**: hotel reservation for Annual Meeting. For details see ICBDSDR website.

*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*