



International Clearinghouse for Birth Defects Surveillance and Research Monthly Newsletter

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What's Going on Regarding Birth Defects

We are glad to inform you that a statement, calling for policy and funding in support of the strengthening of prevention and care of congenital disorders, has been recently published in *JAMA Pediatrics* (abstract available at <http://archpedi.jamanetwork.com/article.aspx?articleid=2529986>, full paper available on request at centre@icbdsr.org). It's a consensus statement from last September's Dar es Salaam conference (7th International Conference on Birth Defects and Disabilities in the Developing World).

Zika Virus:

- ✓ From August 2016 issue of the *World Health Organization Bulletin*: "Information needed for Zika diagnostic test development". Full text available at <http://www.who.int/bulletin/volumes/94/8/16-171207.pdf>
- ✓ The first paper aiming to launch the "Zika International Registry in pregnancy" has been published in the *Lancet Infectious Disease*: [http://www.thelancet.com/journals/laninf/article/PIIS1473-3099\(16\)30255-9/fulltext](http://www.thelancet.com/journals/laninf/article/PIIS1473-3099(16)30255-9/fulltext)
Further information about the International Registry at <https://epgl.unige.ch/zika-in-pregnancy-registry/>
- ✓ CDC established the US Zika Pregnancy Registry and is collaborating with state, tribal, local, and territorial health departments to collect information about pregnancy and infant outcomes following laboratory evidence of Zika virus infection during pregnancy. Further information at <http://www.cdc.gov/zika/hc-providers/registry.html>

Flour fortification and prevention of Neural Tube Defects (NTDs):

- ✓ Last year an estimated 35,500 babies – an average of 97 a day – were born healthy, without NTDs in 58 countries which implement mandatory programs to fortify flour with folic acid, according to research recently published in *Birth Defects Research Part A: Clinical and Molecular Teratology*. The research also notes that this figure only represents 13.2% of all NTDs that could be prevented globally. See the related editorial at <http://onlinelibrary.wiley.com/doi/10.1002/bdra.23518/full>

News from the ICBDSR Centre and Executive Committee

43rd ICBDSR Annual Meeting and Gastroschisis Workshop: to be held in Magdeburg, Germany, from 18 to 21 September 2016. The Annual Meeting and Workshop are quickly approaching. The final program and abstracts' booklet will be available at www.icbdsr.org on early September. More info is already available also at ICBDSR's website.

World Birth Defects Day-Meeting of Charter Organizations: Before the ICBDSR Annual Meeting, on September 18, there will be also a meeting of the Charter organizations of the World Birth Defects Day (WBDD) in order to prepare the WBDD 2017.

ICBDSR Mortality Project: the Principal Investigators of the studies on mortality have received the full dataset provided by participating registries. A general overview will be delivered at the ICBDSR Annual Meeting (Collaborative Projects session) by the PIs participating in the meeting.

ICBDSR Global Gastroschisis project: a proposal and data collection spreadsheets for a new ICBDSR collaborative project on Global Gastroschisis has been disseminated among member registries (deadline for updating the data available for each registry at the Centre was July 1, 2016). We, the ICBDSR Centre, received data from 25 registries. Data overview will be presented and discussed at the ICBDSR Annual Meeting in Magdeburg.