

# International Clearinghouse for Birth Defects Surveillance and Research Monthly Newsletter

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## What's Going on Regarding Birth Defects

#### ✓ Microcephaly and Zika Virus:

We are glad to circulate the following links to extensive information on Zika from March of Dimes (in both English and Spanish). These materials are useful in educating professionals and the public about the dangers of the virus and steps that can be taken to mitigate risks.

http://www.marchofdimes.org/complications/zika-virus-and-pregnancy.aspx http://www.marchofdimes.org/materials/Zika virus and pregnancy fact sheet.pdf http://www.marchofdimes.org/glue/css-images/ notes/Zika and pregnancy infographic.pdf http://www.marchofdimes.org/glue/css-images/ notes/Zika and mosquitoes infographic.pdf

#### ✓ New Study Estimates the Number of People with Congenital Heart Defects Living in the United States:

Thanks to advancements in medical and surgical care, more people are living longer with congenital heart defects (CHD) than ever before. As people live longer, more of them require specialized ongoing care. However, there is no current information about the number of people currently living with CHD in the United States. In this study, researchers estimated that there were about 2.4 million people (1.4 million adults and 1 million children) living with CHD in the United States in 2010. A study recently published in Circulation highlights the need for improved planning of health services to meet the needs of an ever growing population (U.S. adults living with CHD) and development of a system to better track the number of people across all ages living with CHD in the United States. Full paper available at <a href="http://circ.ahajournals.org/content/early/2016/06/30/CIRCULATIONAHA.115.019307">http://circ.ahajournals.org/content/early/2016/06/30/CIRCULATIONAHA.115.019307</a>

For More Information:

- Facts about CHD: <u>http://www.cdc.gov/ncbddd/heartdefects/index.html</u>
- Living with CHD: <a href="http://www.cdc.gov/ncbddd/heartdefects/living.html">http://www.cdc.gov/ncbddd/heartdefects/living.html</a>
- CDC's Tracking and Research of CHD: <u>http://www.cdc.gov/ncbddd/heartdefects/research.html</u>

### News from the ICBDSR Centre and Executive Committee

**43**<sup>rd</sup> **ICBDSR Annual Meeting**:to be held in Magdeburg, Germany, from 18 to 21 September 2016. Participants are kindly requested to make hotel reservation directly at Herrenkrug Parkhotel (<u>empfang@herrenkrug.de</u>), mentioning: "ICBDSR 2016 – Clearinghouse". A block of rooms at preferential rate is available until <u>July29, 2016</u>. Information on registration fee, hotel rates and hotel contacts are available in the Annual Meeting area of the ICBDSR website <u>www.icbdsr.org</u>.

**ICBDSR Mortality Project:** the final deadline for providing data was July 15, 2016. The Principal Investigators of these studies will receive the full data-set by the next days, in order to start the data analysis.

**ICBDSR Global Gastroschisis project:** a proposal and data collection spreadsheets for a new ICBDSR collaborative project on Global Gastroschisis have been disseminated among member registries (deadline July 1, 2016). We received at the ICBDSR Centre the data from 19 registries. The co-Investigators of the project will start preliminary analyses soon and these data will be presented and discussed during the Annual Meeting in Magdeburg (September 18-22, 2016).