



## International Clearinghouse for Birth Defects Surveillance and Research Monthly Newsletter

June 2018

Issue 2018-6

### What's Going on Regarding Birth Defects

A paper by Lorenzo Botto and Pierpaolo Mastroiacovo titled "From cause to care: Triple surveillance for better outcomes in birth defects and rare diseases" has been published in *European Journal of Medical Genetics*. Authors propose three enhancements to improve the value of surveillance. First, merge: eliminate the largely artificial separation between birth defects and rare diseases in surveillance. Second, expand the scope of surveillance to 'triple surveillance': include in surveillance the three components of the causal chain from primary cause (e.g., folic acid insufficiency) to disease occurrence (e.g., spina bifida prevalence) and further to health outcomes (e.g., mortality, morbidity). Third, integrate public health with clinical surveillance: streamline data collection (avoid 'recreational data collection') and use the data rapidly not only for epidemiologic assessment but also for evaluation and improvement of clinical care.

*From cause to care: Triple surveillance for better outcomes in birth defects and rare diseases. Eur J Med Genet. 2018 Jun 11. pii: S1769-7212(18)30169-1. doi: 10.1016/j.ejmg.2018.06.007. [Epub ahead of print]*

Abstracts available at <https://www.ncbi.nlm.nih.gov/pubmed/?term=29902591>

Full PDF available on request at [centre@icbdsr.org](mailto:centre@icbdsr.org)

Authors of a recent study published in *Environment International* examined and compared the associations between extreme heat and Congenital Heart Disease (CHD) phenotypes in summer and spring, assessed their geographical differences, and compared different heat indicators. CHD cases and controls (without major structural defects) have been identified by the National Birth Defects Prevention Study, a US multicenter, population-based case-control study. While generally null results were found, long duration of unseasonable heat was associated with the increased risks for Ventricular Septal Defects (VSDs) and Atrial Septal Defects (ASDs), mainly in South and Northeast of the US.

*Maternal ambient heat exposure during early pregnancy in summer and spring and congenital heart defects - A large US population-based, case-control study. Environ Int. 2018 Jun 7;118:211-221. doi: 10.1016/j.envint.2018.04.043. [Epub ahead of print]*

Abstract available at <https://www.ncbi.nlm.nih.gov/pubmed/29886237>



### Meeting on World Birth Defects Day

We are glad to announce that a meeting on World Birth Defects Day-WBDD is planned in the afternoon of Sunday September 30<sup>th</sup> (2:00 pm -6:00 pm) at Hotel Olšanka in Prague, Czech Republic (the day before the ICBDSR Annual Meeting). All the WBDD Charter and Participating Organizations are invited to attend the meeting. ICBDSR welcome all the participants to attend the entire ICBDSR Annual Meeting. Information on hotel reservation and logistics at <http://www.icbdsr.org/45th-icbdsr-annual-meeting/>

Follow @WBDD on Twitter <https://twitter.com/wbdday>,

Join WBDD page on Facebook <https://www.facebook.com/WBDDay/>

Visit WBDD website <https://www.worldbirthdefectsday.org/>

## News from the ICBDSR Centre, Executive Committee, and ICBDSR Members

### 45<sup>th</sup> ICBDSR Annual Meeting

The 2018 ICBDSR Annual Meeting will take place in Prague, Czech Republic, from September 30<sup>th</sup> to October 4<sup>th</sup>. The preliminary program and information on registration and logistics are available at <http://www.icbdsr.org/45th-icbdsr-annual-meeting/>.

Please don't forget to make your hotel reservation by **June 30<sup>th</sup> 2018** –extended deadline- by email at [rezervace@hotelolsanka.cz](mailto:rezervace@hotelolsanka.cz) mentioning the “ICBDSR” password. No cancellation fee will be charged in the event of cancellation of these reservation. Prague is one of the most desired tourist destinations in Europe, so the early reservation is crucial.

**EUROCAT Registry Leaders Meeting (RLM)** and the **14<sup>th</sup> EUROCAT Scientific Symposium on Future perspectives for congenital anomaly research** has taken place on the 13<sup>th</sup>– 15<sup>th</sup> June 2018 at the European Commission's Joint Research Centre in Ispra, Italy. Several Birth Defects Surveillance Programs also part of ICBDSDR attended the meeting. Lorenzo Botto represented ICBDSDR, delivering an update about our Organization and a lecture on “Triple Surveillance to improve prevention and care of birth defects and rare diseases”

### ICBDSR Alessandra Lisi Award

This award honors Alessandra Lisi, a young researcher at ICBDSDR Centre from 2002 to her untimely death in 2006. The eligibility requirements include an active contribution to the epidemiology or surveillance of birth defects, preferably with an ICBDSDR program, and evidence of a promising research career and ongoing commitment to the field, among others. The deadline for submitting applications to [centre@icbdsr.org](mailto:centre@icbdsr.org) is **June 30, 2018**. Visit ICBDSDR website for full information: <http://www.icbdsr.org/alessandra-lisi-award/>

### Online Self-paced Course on Birth Defect Surveillance and Prevention

The online course is still available for interested professionals. The course has been developed by the International Centre on Birth Defects (ICBD – ICBDSDR Centre), and supported in part by funding from the National Center on Birth Defects and Developmental Disabilities, US Centers for Disease Control and Prevention through Agreement 2016-2017 with the Task Force for Global Health. The course is designed for clinicians, epidemiologists, public health professionals, and anyone interested in understanding birth defects and improving their prevention and care. The course includes videos, quizzes, a discussion forum, and publications/resources. The course is available in English and Spanish. Further information at <http://www.icbdsr.org/online-self-paced-course-on-birth-defect-surveillance-and-prevention/> and the registration form is available at [www.icbdsr.org/course-registration](http://www.icbdsr.org/course-registration). Once registered, you will receive access credentials and can begin the course at your convenience (It is “self-paced”).

## Meetings and Conferences

The **58<sup>th</sup> Annual Meeting of the Teratology Society** will be held on June 23<sup>rd</sup>–27<sup>th</sup>, 2018, at the Hilton Clearwater Beach Resort, in Clearwater, Florida. The theme for this year's meeting is “**Mechanisms, Models, Mothers and Babies: Bringing Birth Defects Research into Practice**”

The **Annual Meeting of European Society of Human Reproduction and Embryology – ESHRE** will be held in Barcelona, Spain, on July 1<sup>st</sup> – 4<sup>th</sup> 2018. See <https://www.eshre.eu/ESHRE2018/Registrations.aspx>

The **International Congress on Advanced Treatments in Rare Diseases (RARE2018)** will take place on 2<sup>nd</sup>-3<sup>rd</sup> July 2018, in London, UK. RARE2018 will address the challenges of Rare Diseases Treatments as well as new therapies on the horizon. Full information at <http://www.rare2018.com/default.aspx>

The **28<sup>th</sup> International Conference on Spina Bifida & Hydrocephalus – Making the Invisible Visible**. 10<sup>th</sup> – 12<sup>th</sup> August, 2018 – Le Meridien, New Delhi, India <http://ifsbhcon2018.com/index.php>

The **Neonate 2018 – 2<sup>nd</sup> International Symposium for Asia**. November 23<sup>rd</sup> – 25<sup>th</sup>, 2018, Shanghai, China. Full information at <https://www.mcascentificevents.eu/the-neonate/>

Website: [www.icbdsr.org](http://www.icbdsr.org)  
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