



Monthly Newsletter

International Clearinghouse for Birth Defects Surveillance and Research

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World Birth Defects Day – March 3, 2016

The Charter Partners Organizations delivered on November 10th the “World Birth Defects Day Charter Document”. It is available at www.icbdsr.org, in the World Birth Defects Day section. Please read the document and if your organization is interested to be recognized as “Participating Organization of World Birth Defects Day”, please fill in the Application Form, available at www.icbdsr.org, and send it to centre@icbdsr.org

What’s Going on Regarding Birth Defects

- A paper on “**Survival of Children With Hypoplastic Left Heart Syndrome**” has been recently published in Pediatrics, by Csaba Siffel et al. Infants with nonsyndromic HLHS born between 1979 and 2005 were identified through the Metropolitan Atlanta Congenital Defects Program. Vital status was ascertained through 2009 based on linkage with vital records. The study showed that survival to adolescence of children with nonsyndromic HLHS born in metropolitan Atlanta has significantly improved in recent years, with those born full term, with normal birth weight, or in a low-poverty neighborhood having a higher survival probability. Survival beyond infancy to adolescence is high.
Abstract available at <http://www.ncbi.nlm.nih.gov/pubmed/26391936>, full article available on request at centre@icbdsr.org
- **November 17 is World Prematurity Day.** Add your voice to raise awareness! Join the Thunderclap campaign: <https://www.thunderclap.it/projects/31695-world-prematurity-day?locale=en>
- The **3rd European Congress on Preconception Health and Care** will take place in Uppsala (Sweden) from 17 to 18 February 2016. Further information at <http://www.pubcare.uu.se/ecphc2016/>. A Facebook-event has been created for the congress: <https://www.facebook.com/events/1653934538184347/>, and there is also a Facebook-page for The PrePreg Network: <https://www.facebook.com/prepregnetwork>

News from the ICBDSR Centre and Executive Committee

- At the recent meeting of the **National Birth Defects Prevention Network** held in the Washington DC area, the **Texas program** was honored to receive several awards. Dr. Mark Canfield received the Godfrey Oakley award, recognizing lifetime achievement in the field of birth defects. Dr. Peter Langlois was given the Network’s President award, for important statistical projects he led in the last couple of years on time monitoring and classification of birth defects. Finally, the Texas program was recognized with the “State Leadership” award.
Also, Dr. John Carey, Clinical Geneticist/Dysmorphologist at the University of Utah and a colleague of Clearinghouse members, received the Godfrey Oakley award for lifetime achievement.
- At the **2015 Excellence in Research Awards** November 4, 2015, the **University of Mississippi Medical Center (UMMC)**, Department of Research, recognized faculty who achieved extramural funding at one of four levels: bronze, silver, gold and platinum. A platinum recipient was Dr. Adolfo Correa, professor of Medicine and interim director of the Jackson Heart Study, and affiliate member of the Clearinghouse. He researches the role of lifestyle and environmental factors in observed health disparities, such as increased rates of cardiovascular disease and diabetes.
- **ICBDSR Mortality Study:** a high number of positive responses have been collected for participation in the mortality study. There are also several candidates as Principal Investigator for the different studies. The Executive Committee and the Centre Director are contacting each P.I. in order to assign the appropriate tasks.
- We welcome two **new Affiliate Members** in the Clearinghouse community:
 - ✓ Dr. **Aliyu Labaran Dayyabu**, Head of Perinatal Medicine Unit of the Obstetrics and Gynecology Department at Abubakar Tafawa Balewa University, Teaching Hospital in Bauchi (Nigeria). Dr. Aliyu has established a group “Collaborative care unit for the Diagnosis [Prenatal] and Management of Congenital Fetal Anomalies”. This group has a Pediatric Surgeon, a Neonatologist and himself as members. Apart from cases that they diagnose and manage, they also collect cases referred to their hospital. They have opened a register for recording cases of congenital anomalies that they have seen. The group also started a study on knowledge of causes, treatment and prevention of congenital anomalies within their hospital community.
 - ✓ Prof. **Paola Manduca**, Geneticist, retired recently from the University of Genova, Italy, where she has been Associate Professor in Genetics. She is still coordinating projects in Italy and Gaza, Palestine and she is involved in collaboration with a project that is taking shape in Eastern Africa. These projects revolve on registration of birth defects and have collateral analytical and molecular research “offspring”.
- Please remember there are some **resources available in the members’ area of the ICBDSR website:** Interesting Lectures, PEACE (Population Estimate of Attributable Fraction of Congenital Conditions Everywhere), and PreSurvSuite.