



## Monthly Newsletter From the International Clearinghouse

February 2014

Issue 2014 - 2

### What's going on regarding birth defects

#### 2014 Surgeon General's Report on Smoking and Health (US)

This year's report concludes that **smoking during pregnancy can cause a baby to be born with cleft lip and/or cleft palate**. Since there are over 7,000 babies a year in the United States born with an orofacial cleft, this has a significant public health impact. The report notes that there may also be a correlation between smoking during pregnancy and a baby being born with clubfoot, gastroschisis, atrial septal defect, or ADHD, but more studies are needed. Quitting smoking BEFORE CONCEPTION can be hard, but it is one of the best ways a woman can protect herself and her baby's health.

#### Screening for Critical Congenital Heart Disease (CCHD).

Critical congenital heart disease (CCHD) is one of the leading causes of death in infants less than one year old. Pulseoximetry screening is a simple, inexpensive test that can detect most cases of seven specific CCHDs in infants: hypoplastic left heart syndrome, pulmonary atresia (with intact atrial septum), tetralogy of Fallot, total anomalous pulmonary venous return, transposition of the great arteries, tricuspid atresia, and truncus arteriosus. In September 2011, the U.S. Secretary of Health and Human Services approved the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children recommendation to add CCHD screening using pulse oximetry to the Recommended Uniform Screening Panel (RUSP). Here the US breakdown on pulse oximetry screening:

Regulatory Addition to Newborn Screening Panel	3
Legislation Enacted	31
Active Legislation	6
Multi-Center Screening or Pilot Project	4
No Action	6
Total States	50

### News from members

#### Texas House Bill 740, legislation requiring CCHD screening for all newborns in Texas, was signed into law in June 2013.

According to the Texas Birth Defects Registry, from 2005-2009, 2,582 babies were born with at least one CCHD. Approximately 20% of CCHDs are not prenatally diagnosed or diagnosed prior to discharge from the hospital nursery. Using these data, it is expected that about 100 infants born in Texas can potentially benefit from pulse oximetry screening each year. Screening soon after birth can help identify newborns with CCHDs early on, allowing them to receive prompt treatment that may help prevent early death or disability. (December 2013 Issue of the "Texas Birth Defects MONITOR - A Semi-Annual Data and Research Update")

The National Registry of Congenital Anomalies of Argentina (RENAC) announced the release of the **RENAC Annual Report 2013**. PDF file (in Spanish) available at: [http://www.msal.gov.ar/images/stories/bes/graficos/0000000344cnt-reporte\\_anual\\_2013\\_RENAR.pdf](http://www.msal.gov.ar/images/stories/bes/graficos/0000000344cnt-reporte_anual_2013_RENAR.pdf)

### News from the Headquarter and Executive Committee

- 2014 Edition of the **Training Program on Surveillance and Prevention of Birth Defects and Preterm Births** (Geneva, WHO Headquarters, 7-11 July 2014): the ICBDSDR Centre received 56 applications from 35 Countries. The members of the Organizing Committee - from WHO, CDC and ICBDSDR- are evaluating the applications. A response about evaluation results will be given not before February 15 (the Training Program is limited to 27 participants to promote extensive interaction and discussion).
- **Clearinghouse listserv** (discussion group): some guidelines for the use of the listserv were recently disseminated among members. This listserv, launched last year, is a members-only forum to discuss the birth defect issues that you most care about. We look forward to your active participation and hope you find it useful.
- **The ICBDSDR Executive Committee** will meet on March 6-7, 2014 at the Headquarter Centre in Rome.

### Upcoming deadlines

- **February 20, 2014:** data for the **1st quarter 2013**, to be published in the **Quarterly Report/Krystalos**.
- **February 28, 2014:** updated description of your program and list of papers published in 2013, to be published in the forthcoming Annual Report.
- **April 30, 2014:** deadline for application to the Alessandra Lisi Award. Details at [www.icbdsr.org](http://www.icbdsr.org)
- **April 30, 2014:** deadline for exemption request of 2014 dues payment
- **June 1, 2014:** deadline for submission of abstracts to be presented at the 41<sup>th</sup> Annual ICBDSDR Meeting (more info will be available shortly on the website).

**SAVE THE DATE: 13-16 September 2014, 41<sup>st</sup> Annual ICBDSDR Meeting in Helsinki, Finland**