



International Clearinghouse for Birth Defects Surveillance and Research Monthly Newsletter

March 2019

Issue 2019-3



**March 3rd, the day of #WorldBDDay is over
but the WBDD initiative will continue all year long!
The “WBDD Movement” is born**

Many thanks to all the participants in the WBDD events, in person or through social media, including the Partner Organizations, health professionals, patients and their families, and interested people.

Many thanks to the **March of Dimes** for hosting the **#WorldBDDay Twitter Chat** on March 1, 2019. During this hour long event, the host tweeted 12 questions to raise awareness about birth defects globally. Many users joined the bilingual Twitter chat, and actively tweeted answers to the questions raised: 160 contributors posted 1,583 tweets, with an estimated 1,269,947 reached accounts and 6,380,682 impressions. “Reached accounts” refer to the total number of people who have seen a tweet, “impressions” refer to the number of times a tweet has been displayed on a screen

An important contribution to the WBDD came from **World Health Organization**, through a live session **“Q&A on Birth Defects”** on Facebook that generated hundreds of comments/questions/shares. The video is available at <https://www.facebook.com/WHO/videos/874188436257174/>.

We also want to highlight the publication of **“A consensus statement on birth defects surveillance, prevention, and care in Latin America and the Caribbean”** in the Pan American Journal of Public Health. There is a full section on WBDD and the consensus statement is the first article in the section. See the full section at <https://www.paho.org/journal/en/international-health-days/world-birth-defects-day>.

To date, 168 organizations enrolled as Partner Organizations in the WBDD on March 3rd. The full list is available in the WBDD website: <https://www.worldbirthdefectsday.org/partners/>. The enrollment continues, **join the WBDD as a Partner Organization** by completing the online application form on the WBDD website <https://www.worldbirthdefectsday.org/application-form/>.

Please note that to have an event qualified as a “WBDD event”, it must be performed **between January 1, and April 30, 2019**. Send information on your event to pierpaolo.mastroiacovo@gmail.com to have it posted on the WBDD website, under “Activities”. Review examples at <https://www.worldbirthdefectsday.org/organize-an-event/>.

Save the date

To observe the World Birth Defect Day, **World Health Organization** is organizing a **webinar on Birth Defects**.

Join the WHO Webinar:

Date: Friday 22 March 2019

Time: 15h00 CET (60 minutes)

WebEx link: <https://who.webex.com/who/j.php?MTID=mac06233de4606b93297946983de5f4c2>

Meeting number: 925 465 160

Last but not least

We recommend that you **create a Twitter account** (institutional and/or personal) if not yet done, in order to keep informed on WBDD activities. Look for the hashtag *#WorldBDDay* and *#ManyBirthDefects1Voice* to find the most recent tweets and to post your tweets.

Follow @worldbdday on Twitter <https://twitter.com/WorldBDDay> and Instagram worldbdday <https://www.instagram.com/worldbdday/>

Join WBDD page on Facebook <https://www.facebook.com/WBDDay/>
Visit WBDD website <https://www.worldbirthdefectsday.org/>

What's Going on Regarding Birth Defects

- Two papers on **Data Quality Indicators** have been published in Birth Defects Research:

Authors developed a list of 40 data quality indicators (DQI) of birth defects surveillance. These DQI address ascertainment, description, coding, and classification and can be used widely to assess the quality of data relative to birth defects of major clinical and public health impact. The proposed list of DQI can be used in surveillance program as a way to document the quality of the program; detect variations within and between programs, and support quality improvements.

Groisman B, Mastroiacovo P, Barbero P, Bidondo MP, Liascovich R, Botto LD. *A proposal for the systematic assessment of data quality indicators in birth defects surveillance*. Birth Defects Res. 2019 Feb 11. doi: 10.1002/bdr2.1474. Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/30746866>

The DQI were applied to data from the National Network for Congenital Anomalies of Argentina (RENAC). DQI provided a focus for improving quality, making decisions, and advocating for interventions.

Groisman B, Barbero P, Mastroiacovo P, Botto LD, Bidondo MP, Liascovich R. *Application of quality indicators to data from the National Network of Congenital Anomalies of Argentina*. Birth Defects Res. 2019 Feb 13. doi: 10.1002/bdr2.1472. Abstract: <https://www.ncbi.nlm.nih.gov/pubmed/30756506>

- A recent Editorial published in Birth Defects Research, entitled “*Teratology Society position statement on surveillance and prevalence estimation of neural tube defects*” acknowledges the value of accurate measurement of total prevalence of neural tube defects (NTDs) in the population to support prevention, and advocates for rigorous surveillance worldwide. Full text available at <https://onlinelibrary.wiley.com/doi/epdf/10.1002/bdr2.1434>.
- The People and Organizations United for Spina Bifida and Hydrocephalus (PUSH!) Global Alliance created scorecards to rate country-level performance on spina bifida, including folate status among women of reproductive age, birth prevalence and mortality associated with spina bifida, prevention strategies, access to care, and the country's engagement in the UN Convention on the Rights of Persons with Disabilities. A total of 187 countries were examined based on a criteria-based scoring system represented by stars (<http://www.pu-sh.org>). This paper, published in Preventive Medicine, summarized scores by Human Development Index (HDI) classification spanning six World Health Organization (WHO) regions. This is the first time country-level performance for spina bifida research,

prevention, and care, grouped by HDI and WHO region has been examined. Policy-makers and stakeholders can use the authors' analyses as benchmarks in their efforts to improve spina bifida surveillance, prevention, and care and to close gaps.

Scorecard for spina bifida research, prevention, and policy: Score analysis by Human Development Index and WHO region. Prev Med. 2019 Feb 11;123:1-7. doi: 10.1016/j.ypmed.2019.02.020. [Epub ahead of print]. Abstract available at <https://www.ncbi.nlm.nih.gov/pubmed/30763626>.

- In case you missed the **MotherToBaby– Society for Maternal Fetal Medicine – The Teratology Society joint webinar** on pregnancy registries, here's a link to *part 1-Current and Future Trends in Research with Pregnant and Lactating Women* <http://bit.ly/PregResearch1>, and to *part 2-Using Registries and Crowd Sourcing to Conduct Research with Pregnant and Lactating Women* <http://bit.ly/PregResearch2> (Lectures registered in January 2019).

News from the ICBD SR Centre, Executive Committee, and ICBD SR Members

Online Self-Paced Course on Birth Defect Surveillance and Prevention

The online course remains available for interested professionals. The course has been developed by the International Centre on Birth Defects (ICBD – ICBD SR 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. It is available in English and Spanish. To date, 165 applicants from 41 countries have participated in the course. Further information is available at <http://www.icbdsr.org/online-self-paced-course-on-birth-defect-surveillance-and-prevention/>. The registration form is available at www.icbdsr.org/course-registration. Once registered, you will receive an email with guidance on how to register by yourself in the Course platform www.icbdsrtraining.org and how to self-enroll in the self paced courses in either English or Spanish.

Meetings and Conferences

2nd World Congress on Maternal Fetal Neonatal Medicine. April 4-6, 2019, London, United Kingdom. <https://www.mcascentificevents.eu/worldmfnm/>

ECPCA – European Cleft Palate Craniofacial Association. June 12-15. 2019, Utrecht, The Netherlands. Theme of the congress is “*Future perspectives in research & therapy*”. Abstracts submission is open. <http://ecpca.eu/>

59th Annual Meeting of the Teratology Society, June 22–26, 2019, San Diego, California, US. The theme for the meeting is “*Sea Changes in Birth Defects Research and Prevention*”. The program offers an exciting variety of scientific sessions, and three workshops will be offered: Current Topics and Updates for Pregnancy Registries, Multidisciplinary Research Needs, and Irresponsible Conduct of Research: What Happens When Things Go Wrong. <http://teratology.org/meetings/2019/>

3rd Congress of Joint European Neonatal Societies. September 17-21, 2019, Maastricht, The Netherlands. <https://www.mcascentificevents.eu/jens/>

2nd International Comprehensive Cleft Care Workshop: Education for Sustainable Cleft Care, October 16-18, 2019 Hilton Lima Miraflores, Lima, Peru. <https://cleftworkshop.org/>

9th International Conference on Birth Defects and Disabilities in the Developing World (ICBD 2019) – “Health for all: Accelerate Efforts for Birth Defects Prevention and Care”. October 23-26, 2019, Colombo, Sri Lanka. **Abstract submission is open!** Abstracts will be accepted until April 30, 2019 (11:59 pm EST). Link to ICBD 2019 – Online Abstract Submission System. <https://slma.lk/icbd2019/abstracts/>

13th Asia Pacific Conference on Human Genetics, November 7-9, 2019, Makati Shangri-la Manila, Philippines. The theme of the conference is “Advancing Translational Medicine and Collaborations in Genomics.” This conference will bring together an outstanding community of faculty, scientists, researchers, and students from the Asia Pacific region and different parts of the world. Everyone is invited to submit abstracts by March 7, 2019. www.apchg2019.org

SAVE THE DATE – 46th ICBDSR Annual Meeting

The 2019 ICBDSR Annual Meeting will take place in **Bratislava, Slovak Republic** from **September 8-11, 2019**. The meeting will be hosted by the Slovak Medical University in Bratislava, Faculty of Public Health. Go to <http://www.icbdsr.org/46th-icbdsr-annual-meeting/> for travel information, link to hotel booking, details on registration fee, and social events.

Interested colleagues are invited to submit abstracts for oral and/or poster presentation at the Scientific Sessions of the ICBDSR Annual Meeting.

Topics may include, but are not limited to:

- Birth defects surveillance and related methodological issues
- Epidemiology of specific defects or groups of defects
- Environmental agents and birth defects
- Infectious agents and birth defects
- Lifestyle factors and birth defects
- Medications and birth defects
- Occupational exposures and birth defects
- Molecular genetics / molecular epidemiology / epigenetics and birth defects
- Prenatal screening, early pregnancy / birth / postnatal outcomes
- Newborn screening disorders
- Rare diseases
- Undiagnosed diseases
- Psychosocial impacts of birth defects, quality of life, education and other related issues

The abstract text should not exceed 350 words, excluding the abstract header. The abstract header should include the title, author(s), and affiliation(s). Acronyms and abbreviations should be spelled out on first use. The abstract text should be structured using the following sub-headings: Background/Objectives, Methods, Results, and Discussion.

The abstract is to be submitted using the electronic abstract submission form that will be available on the ICBDSR website starting in May. Deadline for submission of abstracts is **May 31st, 2019**.

The Annual Meeting Committee will peer-review the abstracts and will make the final decisions regarding acceptance of abstracts and designated presentation format. You will receive an email of notification regarding acceptance of abstracts by June 30th, 2019.

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