



International Clearinghouse for Birth Defects Surveillance and Research Monthly Newsletter

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World Birth Defects Day - WBDD

To date, 147 organizations have enrolled as Partner Organizations in the **2019 WBDD on March 3rd**. The full list is available in the WBDD website: <https://www.worldbirthdefectsday.org/partners/>.

The theme of the 2019 WBDD is: **“Many birth defects, one voice”**. This theme should be used by event organizers as the subtitle of the 2019 WBDD. Twitter Hashtag: *#Manybirthdefects1voice*.

The WBDD day is approaching! Please follow these recommendations in order to observe the Day:

- ✓ Use the WBDD Logo: Copy and paste the logo into documents, flyers, posts, tweets, etc. The logo is available at <https://www.worldbirthdefectsday.org/use-wbdd-logo/>
- ✓ Organize an event (e.g. scientific meeting, educational meeting, or leisure event, such as a marathon). Follow the suggestions at <https://www.worldbirthdefectsday.org/organize-an-event/>. To have an event qualify as a “WBDD event”, it must be performed **between January 1 and April 30, 2019**. Send the relevant information on your event to pierpaolo.mastroiacovo@gmail.com. It will be posted on the WBDD website, in the section “Activities”.
- ✓ Disseminate a story related to your organization’s activities. See suggestions at <https://www.worldbirthdefectsday.org/send-your-story/> and send the story to pierpaolo.mastroiacovo@gmail.com. It will be posted on the WBDD website, in the section “Stories”.

Join the WBDD as a Partner Organization by completing the online application form on the WBDD website <https://www.worldbirthdefectsday.org/application-form/>

Follow @worldbdday on Twitter <https://twitter.com/WorldBDDay>
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

A study from Alberta, Canada aimed to review cases with spina bifida (SB) to provide a possible explanation as to why SB is still prevalent in Alberta. Cases with SB born between 2001 and 2015 and ascertained by the Alberta Congenital Anomalies Surveillance System were reviewed. The notice of birth forms were reviewed to determine folic acid (FA) supplement use before and/or during pregnancy. Socioeconomic status (SES) was also examined. The majority of cases were isolated (58%). The total prevalence of SB for 2001-2015 was 0.37/1,000 births, with isolated SB being 0.21/1,000 births. Urinary and congenital heart defects were the most frequently identified associated anomalies. FA supplementation could not be determined for 69% of cases because of a lack of completeness of the notice of birth forms. There was no statistically significant difference in SES between mothers of cases and all mothers in Alberta. It is important to examine cases with isolated SB to determine why mandatory FA fortification has not completely prevented SB and to identify

which cases are not folate-responsive. A more concerted effort of public health education and promotion with the identification of women with suboptimal folate status and a better understanding of the role of other micronutrients is necessary.

Prevalence rates of spina bifida in Alberta, Canada: 2001–2015. Can we achieve more prevention?

Birth Defects Res. 2018 Dec 18. doi: 10.1002/bdr2.1438. [Epub ahead of print]. Full text available on request at centre@icbdsr.org

Nutrition Folate Task Team – A global nutrition Task Team for the control of folate insufficiency and folic acid responsive neural tube defects launched the webinar *“Using laboratory folate status assessment to strengthen neural tube defect prevention: a regional training approach”*. To learn how more about how the Folate Task Team at Nutrition International has partnered with the Centers for Disease Control and Prevention (CDC) and the CDC Foundation to develop a laboratory capacity building program to measure blood folate levels, using the microbiologic assay plan to join the webinar, which will be held on March 4, 2019.

Register at <http://bit.ly/FolateTaskTeamWebinarMar4>

By attending this webinar, you will learn:

- How folate status assessment can further NTD prevention
- Why the Microbiologic Assay is considered the “gold standard” for folate assessment
- What the goals and objectives are of the CDC training curriculum
- Details on the innovative regional approach to laboratory training including information on a newly developed training video
- The impact the training has on laboratories

For more information about the Folate Task Team: <https://www.nutritionintl.org/what-we-do/nteam/folate-task-team/>

News from the ICBDSR Centre, Executive Committee, and ICBDSR 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 – ICBDSR 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, 146 applicants from 37 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

Congenital CMV – From Pregnancy to Infancy: Let's Face It. February 21-22, 2019, Florence, Italy. <https://www.mcascientificevents.eu/cm/>

2nd International Congress on Advanced Treatments in Rare Diseases (RARE2019). March 4-5, 2019, Vienna, Austria. <http://www.rare2019.com/>

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

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://www.teratology.org/meetings/2017/>

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. The call for abstracts will be disseminated at a later time.

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