



International Clearinghouse for Birth Defects Surveillance and Research Monthly Newsletter

November 2019

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News from the ICBDSR Executive Committee, ICBD/ICBDSR Centre, and ICBDSR Members

Collaborative Publications

The ICBDSR collaborative paper on **“Analysis of Mortality among Neonates and Children with Spina Bifida: An International Registry-Based Study, 2001-2012”** is now published online as an open-access article and is published in the November issue of Paediatric and Perinatal Epidemiology:

<https://onlinelibrary.wiley.com/doi/full/10.1111/ppe.12589>

Bakker MK, Kancherla V, Canfield MA, Bermejo-Sanchez E, Cragan JD, Dastgiri S, DeWalle HEK, Feldkamp ML, Groisman B, Gatt M, Hurtado-Villa P, Kallen K, Landau D, Lelong N, Lopez Camelo JS, Martínez L, Morgan M, Mutchinick OM, Nembhard WN, Pierini A, Rissmann A, Sipek A, Szabova E, Tagliabue G, Wertelecki W, Zarante I, Mastroiacovo P. *Analysis of Mortality among Neonates and Children with Spina Bifida: An International Registry-Based Study, 2001-2012*. *Paediatr Perinat Epidemiol*. 2019 Nov;33(6):436-448. doi: 10.1111/ppe.12589. Epub 2019 Oct 21. PubMed PMID: 31637749.

From ICBD – International Centre on Birth Defects

Our International Centre on Birth Defects (ICBD) will participate in the Birth Defects Surveillance Workshop, organized by WHO-AFRO with the help of CDC and ICBD. The Workshop will take place in Kampala, Uganda, November 11-15. ICBD faculty includes Dr. Boris Groisman, RENAC program and ICBDSR Vice Chair. Teams from several African countries are expected to participate.

What's Going on Regarding Birth Defects: a selection from the recent literature

All readers are kindly invited to contribute to this section of the Newsletter, sending their suggestions to centre@icbdsr.org by the 1st Friday of the month.

Long AM, Bunch KJ, Knight M, Kurinczuk JJ, Losty PD; BAPS-CASS. *One-year outcomes of infants born with congenital diaphragmatic hernia: a national population cohort study*. *Arch Dis Child Fetal Neonatal Ed*. 2019 Nov;104(6):F643-F647. doi: 10.1136/archdischild-2018-316396. Epub 2019 Jun 1. PubMed PMID: 31154421.

Best KE, Seaton SE, Draper ES, Field DJ, Kurinczuk JJ, Manktelow BN, Smith LK. *Assessing the deprivation gap in stillbirths and neonatal deaths by cause of death: a national population-based study*. *Arch Dis Child Fetal Neonatal Ed*. 2019 Nov;104(6):F624-F630. doi: 10.1136/archdischild-2018-316124. Epub 2019 Mar 6. PubMed PMID: 30842208.

Mathews F, Shaffer AD, Georg MW, Ford MD, Goldstein JA, Jabbour N, Simons JP. *Airway anomalies in patients with craniosynostosis*. *Laryngoscope*. 2019 Nov;129(11):2594-2602. doi: 10.1002/lary.27589. Epub 2018 Nov 19. PubMed PMID: 30456762.

Grant GB, Desai S, Dumolard L, Kretsinger K, Reef SE. *Progress Toward Rubella and Congenital Rubella Syndrome Control and Elimination - Worldwide, 2000-2018*. *MMWR Morb Mortal Wkly Rep*. 2019 Oct 4;68(39):855-859. doi:10.15585/mmwr.mm6839a5. PubMed PMID: 31581161; PubMed Central PMCID: PMC6776377.

Money D, Lee T, O'Brien C, Brophy J, Bitnun A, Kakkar F, Boucoiran I, Alimenti A, Vaudry W, Singer J, Sauve LJ; Canadian Perinatal HIV Surveillance Program. [Congenital anomalies following antenatal exposure to dolutegravir: a Canadian surveillance study](#). *BJOG*. 2019 Oct;126(11):1338-1345. doi:10.1111/1471-0528.15838. Epub 2019 Jul 3. PubMed PMID: 31188522.

Wang Y, Luo BR. [The association of body composition with the risk of gestational diabetes mellitus in Chinese pregnant women: A case-control study](#). *Medicine (Baltimore)*. 2019 Oct;98(42):e17576. doi: 10.1097/MD.00000000000017576. PubMed PMID: 31626126.

Zang X, Li S, Zhao Y, Chen K, Wang X, Song W, Ma J, Tu X, Xia Y, Zhang S, Gao C. [Systematic Meta-Analysis of the Association Between a Common NOS1AP Genetic Polymorphism, the QTc Interval, and Sudden Death](#). *Int Heart J*. 2019 Sep 27;60(5):1083-1090. doi: 10.1536/ihj.19-024. Epub 2019 Aug 23. PubMed PMID: 31447468.

Ghali N, Sobey G, Burrows N. [Ehlers-Danlos syndromes](#). *BMJ*. 2019 Sep 18;366:l4966. doi: 10.1136/bmj.l4966. Review. PubMed PMID: 31533917.

What's Going on Regarding Birth Defects: initiatives and announcements

All readers are kindly invited to contribute to this section of the Newsletter, sending their suggestions to centre@icbdsr.org by the 1st Friday of the month.



New Name, New Logo, SAME Critical Mission

The Teratology Society is now the **Society for Birth Defects Research and Prevention (BDRP)**.

The Society announces a new name and logo to celebrate its long history and dedication to protecting the world's most vulnerable population through the combined efforts of scientists and clinicians. As the Society approaches its 60th Anniversary, it's a tribute to the important work done, and clearly communicates the impact and value of its scientific efforts. Read the [President's Message](#) to learn more.

KAP (Knowledge Action Project) was launched by the **WHO Global Coordination Mechanism on Non Communicable Diseases (GDM/NCD)**. It is a community-driven platform for (NCDs information, interaction and inspiration. The KAP aims to create a community of connected individuals from various backgrounds and skill-sets to access knowledge and information, promote collaboration, and find the common goals to beat NCDs. New users can [sign up here](#) and begin connecting with like-minded individuals

KAP Calendar

Staying up-to-date on past, present, and upcoming NCD news and events is now made easier with the calendar in the 'News and Events' section. In the new calendar, KAP users can find information on national, regional and global events on NCDs.

1. Visit: www.who.int/KAP
2. Click the menu bar (found in the upper left-hand corner of the page) and select the 'News and Events' tab and select Upcoming events
3. From the selected tab, you will see a calendar with the dates marked in yellow for the future events and the dates marked in red for the past events. Click on a relevant date to see the list of events scheduled for that day.
4. On the right side of the calendar, you can see an overview of all the events scheduled for the month that you are currently viewing. Those registered users that are also Community members will be able to see in this calendar the events posted by the Community that they are making a part of.
5. If desirable, select another tab from the list or continue to enjoy exploring another section of the KAP.

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 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 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. 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 course in either English or Spanish.

SAVE THE DATE - 2020 ICBDSR Annual Meeting

The 47th ICBDSR Annual Meeting will be held in Bologna, Italy, at the Relais Bellaria Hotel & Congressi., from **October 5 through 7, 2020**. The meeting will be hosted by the Italy Emilia Romagna (IMER) registry, Alma Mater Studiorum University of Bologna. Additional information will be disseminated at a later time.



World Birth Defects Day - WBDD Movement

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> 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/>

Meetings and Conferences

14th Meeting of the International Conference on Rare Diseases and Orphan Drugs” (ICORD), November 11-13, 2019, Israel. The Conference is held with the collaboration of ICORD and Israel Ministry of Health. ICORD is an International Society for all individuals active in rare diseases and/or orphan drugs, including health care, research, academic, industry, patients, patient groups, regulatory authorities, health authorities, and public policy professionals. For further information please visit the ICORD conference website at: www.icord2019.org. Please follow the Conference on [Facebook](#), [Twitter](#), [LinkedIn](#) and share.

12th European Public Health Conference, November 20-23, 2019, Marseille France. <https://ephconference.eu/>

9th International Conference on Birth Defects and Disabilities in the Developing World (ICBD 2020) February 23-26, 2020. Colombo, Sri Lanka. <http://icbd.marchofdimes.org/>

11th Edition of International Conference on Preventive Medicine & Public Health, March 5-6, 2020 Rome, Italy. Theme: Science-based resolutions addressing global pervasive & preventable health issues. <https://preventivemedicine.healthconferences.org/>

Annual Clinical Genetics Meeting of the American College of Medical Genetics (ACMG), March 17-21, 2020
San Antonio, TX, USA. <https://www.acmgmeeting.net/acmg2020/Public/mainhall.aspx>

28th International Conference on Clinical Pediatrics, April 15-16, 2020 London, UK. Theme: Enlightening the
New Horizons in Clinical Pediatrics. <https://clinicalpediatrics.conferenceseries.com/>

EUROCAT Registry Leader Meeting and Scientific Symposium, June 30-July 2, 2020 Valencia (Spain).
<https://eu-rd-platform.jrc.ec.europa.eu/eurocat/news-events>

World Congress of Epidemiology WCE 2020 on “Methodological Innovations in Epidemiology”, September 13-
16, 2019, Melbourne, Australia. <https://wce2020.org/>