



## Monthly Newsletter

June 2024

Issue 2024 -06

### 2024 ICBD SR ANNUAL MEETING

The meeting will celebrate 50 years of ICBD SR (1974 – 2024) and 60 years of congenital anomaly registration in Czech Republic (1964 – 2024).

The **50<sup>th</sup> Annual Meeting of the ICBD SR** will take place in Prague, Czech Republic, from **September 1 to 4, 2024** at the Hermitage Hotel. Information on hotel reservation and registration: [50th ICBD SR Annual Meeting – ICBD SR](#). Please note the deadline of **June 30, 2024**, for hotel booking. Reservations can be made by the “Reservation form” available in the [ICBD SR website](#).

General plan of the meeting:

<b>Sun, Sept 1</b>	Executive Committee (EC) Meeting ( <i>restricted to EC members</i> ) Pre-Annual Meeting Workshop - Enhancing Birth Defect Surveillance: Interactive Case Studies for Quality Improvement <i>Welcome Reception at Hermitage Hotel, offered by ICBD SR</i>
<b>Mon, Sept 2</b>	Scientific Sessions <i>Dinner at the Hermitage Hotel, included in the registration fee of delegates staying at the hotel</i>
<b>Tue, Sept 3</b>	Session on collaborative projects ICBD SR Business Meeting) <i>Tour - personal payment, optional (afternoon), more details to come soon</i>
<b>Wed, Sept 4</b>	Joint Workshop with Czech Society of Medical Genetics and Genomics <i>Departure (afternoon)</i>

Please note: we have added a **Pre-Annual Meeting Workshop** on Sunday, September 1<sup>st</sup>. See the ICBD Corner in the March newsletter for details. There will be no charge to attend the workshop however, registration is required.

Details and registration: <https://surveys.eventsmgtportal.com/s3/ICBD SR-2024-workshop-registration>

### Abstract review and notification

The abstract submission deadline was May 12<sup>th</sup>. Thank you to all who submitted. 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 15, 2024**.

### ICBD corner

A few items this month, including heads-up for upcoming releases and some interesting findings in the world of birth defects.

- First, the heads-up. Here at ICBD we are working with CDC and WHO to complete the second edition of the third and last volume of the Birth Defect Toolkit: Manual for Programme Managers. This Manual has several completely new chapters, including case studies on selected conditions and on quality assessment, as well as teaching modules that you can use for training at your sites. A Spanish translation is also in the works.

- Second, some recent significant findings in the field of common birth defects.
  - One notable discovery involves the gene *Nipbl*, which, when deficient, causes most cases of Cornelia de Lange syndrome. Researchers found that *Nipbl*'s interaction with another gene, *Nanog*, is crucial during early embryonic development. **Misregulation of these genes can lead to various birth defects**, providing new insights into their genetic origins and potential early intervention strategies ([MedXpress](#)).
  - Another promising development is the potential of **adding folic acid to table salt** as a preventive measure against severe birth defects. This approach could significantly reduce the incidence of conditions like spina bifida, emphasizing the importance of sufficient folic acid intake before and during pregnancy ([News | Emory University | Atlanta GA](#)).
  - Finally, researchers at the University of Wisconsin-Madison have identified **disruptions in DNA methylation that affect cranial neural crest cells, leading to orofacial clefts** in mice. This discovery highlights the role of epigenetic changes in the development of certain birth defects and opens avenues for potential therapeutic interventions ([ScienceDaily](#)).

These studies represent a shift from merely understanding birth defects to actively developing methods for early detection and prevention, offering hope for improved outcomes and reduced healthcare costs for affected individuals and their families.

## News from the ICBDSR and the World: a busy quarter of the year ahead

The year's second quarter provides many opportunities to advocate for communities and families impacted by birth defects. Consider putting together local activities and joining our many partners: we are stronger together.

- **June 22-26** is the **Society for Birth Defects Research and Prevention's 64th Annual Meeting: Addressing Disparities in Birth Defects Research and Prevention**. The robust scientific program represents active, timely research areas of high relevance to public health and significant usefulness to researchers in the fields of birth defects research and surveillance and related fields.

Meeting website: <https://www.birthdefectsresearch.org/meetings/2024/>

## Recently published: recent papers selected by ICBDSR

*(in addition to those discussed in ICBDSR corner)*

*To find the paper online, use the DOI for a browser search. If interested but unable to get the full text of the papers, please email us and we will see what we can do to help.*

## Prevention and call to action

### Action against birth defects: if not now, when?

Strong, K., Robb-McCord, J., Walani, S., Mellado, C., Botto, L. D., Lay-Son, G., ... Banerjee, A. (2024) *Global Health Action*, 17(1). <https://doi.org/10.1080/16549716.2024.2354002>

### [A global update on the status of prevention of folic acid-preventable spina bifida and anencephaly in year 2022.](#)

Wagh K, Kancharla V, Dorsey A, Pachón H, Oakley GP Jr. *Birth Defects Res.* 2024 May;116(5):e2343. doi: 10.1002/bdr2.2343. PMID: 38688860

### [Expanding Fortification with Folic Acid: Thinking Outside the Cereal-Grain Box.](#)

Tsang BL, Stadnik C, Duong M, Pachón H, Martinez H. *Nutrients.* 2024 Apr 27;16(9):1312. doi: 10.3390/nu16091312. PMID: 38732559

## Investigating risk factors

## **Teratogenesis, Perinatal, and Neurodevelopmental Outcomes After In Utero Exposure to Antiseizure Medication: Practice Guideline From the AAN, AES, and SMFM.**

Pack AM, Oskoui M, Williams Roberson S, Donley DK, French J, Gerard EE, Gloss D, Miller WR, Munger Clary HM, Osmundson SS, McFadden B, Parratt K, Pennell PB, Saade G, Smith DB, Sullivan K, Thomas SV, Tomson T, Dolan O'Brien M, Botchway-Doe K, Silsbee HM, Keezer MR. *Neurology*. 2024 Jun;102(11):e209279. doi: 10.1212/WNL.0000000000209279. Epub 2024 May 15. PMID: 38748979

## **Maternal obesity, interpregnancy weight changes and congenital heart defects in the offspring: a nationwide cohort study.**

Hedermann G, Hedley PL, Gadsbøll K, Thagaard IN, Krebs L, Hagen CM, Sørensen TIA, Christiansen M, Ekelund CK. *Int J Obes (Lond)*. 2024 May 11. doi: 10.1038/s41366-024-01531-5. Online ahead of print. PMID: 38734850

## **Use of GLP1 receptor agonists in early pregnancy and reproductive safety: a multicentre, observational, prospective cohort study based on the databases of six Teratology Information Services.**

Dao K, Shechtman S, Weber-Schoendorfer C, Diav-Citrin O, Murad RH, Berlin M, Hazan A, Richardson JL, Eleftheriou G, Rousson V, Diezi L, Haefliger D, Simões-Wüst AP, Addor MC, Baud D, Lamine F, Panchaud A, Buclin T, Girardin FR, Winterfeld U. *BMJ Open*. 2024 Apr 24;14(4):e083550. doi: 10.1136/bmjopen-2023-083550. PMID: 38663923

## **A multidisciplinary and structured investigation of three suspected clusters of transverse upper limb reduction defects in France.**

Boudet-Berquier J, Demattei C, Guldner L, Gallay A, Manouvrier S, Botton J, Philippat C, Delva F, Bloch J, Semaille C, Odent S, Perthus I, Randrianaivo H, Babajko S, Barjat T, Beneteau C, Brennetot N, Garne E, Haddad G, Hocine M, Lacroix I, Leuraud K, Mench M, Morris J, Patrier S, Sartelet A, Verloes A, Bonaldi C, Le Barbier M, Gagnière B, Pépin P, Ollivier R, Bitoun M, King L, Guajardo-Villar A, Gomes E, Desenclos JC, Regnault N, Benachi A. *Eur J Epidemiol*. 2024 Apr 27. doi: 10.1007/s10654-024-01125-5. Online ahead of print. PMID: 38671254

## **Birth defects in low-resource areas**

### **Prevalence and associated factors of congenital anomalies in Ethiopia: A systematic review and meta-analysis.**

Mogess WN, Mihretie TB. *PLoS One*. 2024 Apr 30;19(4):e0302393. doi: 10.1371/journal.pone.0302393. eCollection 2024. PMID: 38687732

### **Determinants of externally visible birth defects among perinatal deaths at Adama Comprehensive Specialized Hospital: a case-control study.**

Aman H, Ahmad S, Chala G, Afework M. *BMC Pediatr*. 2024 Apr 20;24(1):260. doi: 10.1186/s12887-024-04729-8. PMID: 38641790

## **Methods**

### **Classification of isolated versus multiple birth defects: An automated process for population-based registries.**

Benjamin RH, Nguyen JM, Drummond-Borg M, Scheuerle AE, Langlois PH, Canfield MA, Shumate CJ, Mitchell LE, Agopian AJ. *Am J Med Genet A*. 2024 May 21:e63714. doi: 10.1002/ajmg.a.63714. Online ahead of print. PMID: 38770996

**Meetings and Events:** A list of future Meetings & Events is available at <http://www.icbdsr.org/meetings/>.

ICBDSR training platform: [www.icbdsrtraining.org](http://www.icbdsrtraining.org)

Facebook: [www.facebook.com/ICBDSR](http://www.facebook.com/ICBDSR)

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