

Monthly Newsletter May 2024

Issue 2024 -05

2024 ICBDSR ANNUAL MEETING

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

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

General plan of the meeting:

Sun, Sept 1	Executive Committee (EC) Meeting (restricted to EC members) Pre-Annual Meeting Workshop - Enhancing Birth Defect Surveillance: Interactive
23, 2001	Case Studies for Quality Improvement
	Welcome Reception at Hermitage Hotel, offered by ICBDSR
Mon, Sept 2	Scientific Sessions
	Dinner at the Hermitage Hotel, included in the registration fee of delegates staying
	at the hotel
Total Caret 3	Session on collaborative projects
Tue, Sept 3	ICBDSR Business Meeting)
	Tour - personal payment, optional (afternoon), more details to come soon
Wed, Sept 4	Joint Workshop with Czech Society of Medical Genetics and Genomics
	Departure (afternoon)

Please note: we have added a Pre-Annual Meeting Workshop on Sunday, September 1st. See the ICBD Corner in the March newsletter for details. There will be no charge to attend the workshop. Registration will be required, and more information will be circulated in the coming months.

Abstracts Submission:

The submission deadline has been extended to May 12th.

We invite you to submit abstracts for oral and/or poster presentation at the 50th ICBDSR Annual Meeting Scientific Symposium, this will be an in-person meeting.

The theme for the 50th Annual Meeting Scientific Symposium will be:

Primary Prevention, Surveillance and Management of Birth Defects

Abstract topics should fit one of the following thematic areas:

- Birth defect surveillance and descriptive epidemiology (including surveillance methodology)
- Risk factors and primary prevention for birth defects
- Rare diseases
- Covid-19 and impact on reproductive outcomes, birth defects surveillance, prevention, and care
- Molecular genetics / molecular epidemiology / epigenetics and birth defects
- Prenatal screening, early pregnancy / birth / postnatal outcomes

- Psychosocial impacts of birth defects, quality of life, education, and other related issues
- Management and care for birth defects
- Patient and caregiver experiences
- Historical perspective of surveillance of congenital anomalies

Authors of accepted oral sessions should aim at 10 minutes presentation with 3-5 minutes questions.

Abstract format

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.

Abstract submission information

The abstract is to be submitted using the electronic <u>abstract submission form</u> in the ICBDSR website. Deadline for submission of abstracts is **May 12, 2024**.

Abstract review and notification

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.

Submit your abstract **HERE**.

OMNI-Net Ukraine Birth Defects Program: donations requested

On behalf of OMNI-Net UBDP, the ICBDSR would like to ask to you please take 5 minutes to view this video: https://youtu.be/Mdmzu2rSEUc.

OMNI-Net UBDP is striving to continue their population-based surveillance under increasingly difficult war circumstances. In this context, they are appealing for personal donations from ICBDSR colleagues and promotion of the appeal among others.

ICBD corner

You and your team may invest quite a bit of time in video webinars on topics you care about. We at ICBD are exploring ways to help disseminate interesting and important information on congenital anomalies and genetic conditions. Here are three videos that have appeared on YouTube in the last year or so.

- Epidemiology of birth defects (with focus on occupations exposures, by Jenil Patel, PhD (Texas, USA): https://www.youtube.com/watch?v=jjw25YNiKsc&t=10s
- Community screening strategies to improve equitable access in diagnosis and management of birth defects: lessons from low and middle-income countries. Several speakers from the Sub Saharan Congenital Anomalies Network.: https://www.youtube.com/watch?v=B7Cvc8labe0
- Case reports and case series: isotretinoin teratogenicity, by Sonja A Rasmussen, MD, MS. https://www.youtube.com/watch?v=fEK8OefXblw

What do you think? If you have suggestions on recent interesting videos and seminars, do send us a comment and we may continue this series in the months to come.

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.

 May 13-15 is the World European Congress on Pediatrics and Neonatal Conference – It will be held in Rome, Italy. The program will grab on both international and regional speakers who are experts in neonatal and pediatric knowledge. Topics would be focused on common and updated scientific knowledge with the theme of "Transforming the Future of Pediatric and Neonatal Medicine: Advancements, Discoveries, and Innovations".

Website: https://kindcongress.com/event/world-european-congress-on-pediatrics-and-neonatal-european-pediatrics-2024/

Email: europeanpediatricsciencie@outlook.com

• 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 ICBD

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.

This month, we focus on recent review papers on various birth defect topics, including outcomes

Review and similar papers

General

Congenital Anomalies in Multiple Pregnancy: A Literature Review.

Shin JE, Ko HS, Bae JY, Seong WJ, Ahn TG, Han YJ, Cho GJ, Park IY. Obstet Gynecol Surv. 2024 Mar;79(3):167-175. doi: 10.1097/OGX.000000000001251.PMID: 38482746

Global air pollution exposure and congenital anomalies: an updated systematic review and meta-analysis of epidemiological studies.

Feng Y, Liu X, Zhang X, Zhao X, Chang H, Ouyang F, Yu Z, Gao Z, Zhang H.Int J Environ Health Res. 2024 May;34(5):2333-2352. doi: 10.1080/09603123.2023.2246383. Epub 2023 Aug 23.PMID: 37610216

Surveillance of multiple congenital anomalies; searching for new associations.

Morris JK, Bergman JEH, Barisic I, Wellesley D, Tucker D, Limb E, Addor MC, Cavero-Carbonell C, Matias Dias C, Draper ES, Echevarría-González-de-Garibay LJ, Gatt M, Klungsøyr K, Lelong N, Luyt K, Materna-Kiryluk A, Nelen V, Neville A, Perthus I, Pierini A, Randrianaivo-Ranjatoelina H, Rankin J, Rissmann A, Rouget F, Sayers G, Wertelecki W, Kinsner-Ovaskainen A, Garne E.Eur J Hum Genet. 2024 Apr;32(4):407-412. doi: 10.1038/s41431-023-01502-w. Epub 2023 Dec 5.PMID: 38052905

Decision-making for congenital anomalies diagnosed during pregnancy: a narrative review.

Pecoriello J, Lilly AG, Jalili D, Mendoza C, Quinn GP, Penfield CA.J Assist Reprod Genet. 2024 Apr 17. doi: 10.1007/s10815-024-03112-x. Online ahead of print.PMID: 38630201

Specific anomalies

<u>European reference network for rare inherited congenital anomalies (ERNICA) evidence based guideline on the management of gastroschisis.</u>

Burgos CM, Irvine W, Vivanti A, Conner P, Machtejeviene E, Peters N, Sabria J, Torres AS, Tognon C, Sgró A, Kouvisalo A, Langeveld-Benders H, Sfeir R, Miserez M, Qvist N, Lokosiute-Urboniene A, Zahn K, Brendel J, Prat J, Eaton S, Benachi A.Orphanet J Rare Dis. 2024 Feb 12;19(1):60. doi: 10.1186/s13023-024-03062-

8.PMID: 38347519

Long-term follow-up of patients with congenital diaphragmatic hernia.

Cimbak N, Buchmiller TL.World J Pediatr Surg. 2024 Apr 9;7(2):e000758. doi: 10.1136/wjps-2023-000758. eCollection 2024.PMID: 38618013.

Maternal exposure to folate antagonists and susceptibility to congenital heart disease in offspring: A systematic review and meta-analysis. Luitel P, Yadav R, Mandal P, Adhikari N, Paudel S, Mudvari A.Br J Clin Pharmacol. 2024 Apr;90(4):933-941. doi: 10.1111/bcp.16021. Epub 2024 Feb 18.PMID: 38369772

Neurodevelopmental Outcomes for Individuals With Congenital Heart Disease: Updates in Neuroprotection, Risk-Stratification, Evaluation, and Management: A Scientific Statement From the American Heart Association.

Sood E, Newburger JW, Anixt JS, Cassidy AR, Jackson JL, Jonas RA, Lisanti AJ, Lopez KN, Peyvandi S, Marino BS; American Heart Association Council on Lifelong Congenital Heart Disease and Heart Health in the Young and the Council on Cardiovascular and Stroke Nursing. Circulation. 2024 Mar 26;149(13):e997-e1022. doi: 10.1161/CIR.000000000001211. Epub 2024 Feb 22.PMID: 38385268

<u>Pulse Oximetry Screening for Critical Congenital Heart Defects in Newborn Babies.</u> Girdhar A, Ewer AK.Crit Care Nurs Clin North Am. 2024 Mar;36(1):99-110. doi: 10.1016/j.cnc.2023.09.001. Epub 2023 Oct 17.PMID: 38296378

Multidisciplinary management of people with spina bifida across the lifespan.

Koch VH, Lopes M, Furusawa E, Vaz K, Barroso U.Pediatr Nephrol. 2024 Mar;39(3):681-697. doi: 10.1007/s00467-023-06067-w. Epub 2023 Jul 28.PMID: 37501019

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

International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR)

Website: <u>www.icbdsr.orq</u>
ICBDSR training platform: <u>www.icbdsrtraining.org</u>
Facebook: <u>www.facebook.com/ICBDSR</u>
Instagram: <u>https://www.instagram.com/icbdsr/</u>
Twitter:@icbdsr <u>https://twitter.com/ICBDSR</u>

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