



Monthly Newsletter

March 2024

Issue 2024 -03

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 **50th 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:

Sun, Sept 1	Executive Committee (EC) Meeting (<i>restricted to EC members</i>) Pre-Congress Workshop – focus on quality improvement <i>Welcome Reception at Hermitage Hotel, offered by ICBD SR</i>
Mon, Sept 2	Scientific Sessions – Meeting room Verdana <i>Dinner at the Hermitage Hotel, included in the registration fee of delegates staying at the hotel</i>
Tue, Sept 3	Scientific Session – Meeting Room Verdana (morning) <i>Tour - personal payment, optional (afternoon), more details to come soon</i>
Wed, Sept 4	ICBD SR Business Meeting and Scientific Session – Meeting room Verdana (morning) <i>Departure (afternoon)</i>

Please note: we have added a Pre-Congress Workshop on Sunday, September 1st. See the ICBD Corner for details.

Abstracts Submission:

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

The theme for the 50th Annual Meeting Scientific Symposium will be updated in our next newsletter.

Abstract topics should fit one of the following thematic areas:

Birth defect surveillance and descriptive epidemiology (including surveillance methodology)

- 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

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

Authors of accepted **posters** must prepare their poster as a **single** Power Point slide in **landscape** orientation and these will be presented digitally on a TV monitor.

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 [abstract submission form](#) in the ICBD SR website.

Deadline for submission of abstracts is **May 1, 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 30, 2024**.

Submit your abstract [HERE](#).

ICBD corner: new workshop offering at the 2024 annual meeting, 1 Sept 2024

High quality birth defect surveillance requires a blend of clinical knowledge and data science, mixed in with a passion for quality improvement: *we can always do better, do fewer errors, be more efficient.*

In this workshop, catered to both novices and seasoned professionals, participants will work in *small groups*, supported by experienced tutors, to *refine their skills in recognizing, diagnosing, and understanding* several major birth defects of clinical and public health importance. Additionally, they will gain insight into the broader context by exploring *fundamental concepts* such as sequences, syndromes, and associations, delving into common syndromes, and examining major risk factors.

To maximize clinical relevance and discussion, *participants will work through carefully crafted case studies* – clinical and well as epidemiologic. They will hone their skills in utilizing *checklists*, interpreting key findings in visual and textual formats, and will be equipped with a smartphone *app tailored to support their practice*. A pre-and-post workshop assessment (anonymously conducted) will enable participants to gauge their progress.

The ideal participant is an enthusiastic champion of birth defect surveillance and prevention, interested or actively engaged in surveillance or clinical activities related to congenital anomalies. The workshop has something for *novice as well as experienced professionals*.

Due to workshop structure, *limited spots* are available. Stay tuned for registration details, or, in the meanwhile, express interest via email to ICBD.

News from the ICBD SR and the World: a busy quarter of the year ahead

The first three months of the year provide 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.

- **March 3 is World Birth Defects Day** – the Clearinghouse is a founding partner of this event, and this year, as in the past, several members will participate in planning activities. We will share information on ideas and activities as these take form. We hope everyone involved in birth defects will do their best to spread the word about birth defects, their impact, and available solutions – better care and better primary prevention.

- Sign up as a WBDD partner at [2023 WBDD Partner Form - World Birth Defects Day](#)
 - The [toolkit of resources](#) is still valid to guide your awareness activities for WBDD.
Twitter: @worldbdday <https://twitter.com/WorldBDDay>
Instagram: worldbdday<https://www.instagram.com/worldbdday/>.
 - Join the WBDD page on Facebook: <https://www.facebook.com/WBDDay/>
- **March 21 is World Down Syndrome Day (WSDS)**, a global awareness day which has been officially observed by the United Nations since 2012.

The date for WSDS being the 21st day of the 3rd month, was selected to signify the uniqueness of the triplication (trisomy) of the 21st chromosome which causes Down syndrome.

Website: <https://www.worlddownsyndromeday.org/>

A selection from the recent literature – new in 2024

Please send suggestions to centre@icbdsr.org by the 1st Friday of the month.

For the full link, hover over the title or use the URL below the authors' names. 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.

Spotlight on congenital heart disease through the lifespan

A personal selection of ten papers in 2024. Hover over the title for the full link. 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.

Prenatal and prevention

- Risk of major congenital heart disease in pregestational maternal diabetes is modified by hemoglobin A1c.
R He, LK Hornberger, A Kaur... - ... in *Obstetrics & ...*, 2024 - Wiley Online Library
<https://obgyn.onlinelibrary.wiley.com/doi/full/10.1002/uog.27456>
- Maternal exposure to folate antagonists and susceptibility to congenital heart disease in offspring: A systematic review and meta-analysis.
P Luitel, R Yadav, P Mandal, N Adhikari... - *British Journal of ...*, 2024 - Wiley Online Library
<https://bpspubs.onlinelibrary.wiley.com/doi/full/10.1111/bcp.16021>
- 733 Perinatal outcomes in pregnancies complicated by a prenatal diagnosis of critical congenital heart disease (CCHD)
F Cody, O Franklin, N Mc Cay, Z Molphy... - *American Journal of ...*, 2024 - ajog.org
[https://www.ajog.org/article/S0002-9378\(23\)01560-0/fulltext](https://www.ajog.org/article/S0002-9378(23)01560-0/fulltext)

Identifying cases beyond birth defect registries

- Machine learning informed diagnosis for congenital heart disease in large claims data source.
AJ Marelli, C Li, A Liu, H Nguyen, H Moroz, JM Brophy... - *JACC: Advances*, 2024 - jacc.org
<https://www.jacc.org/doi/abs/10.1016/j.jacadv.2023.100801>

Outcomes through the lifespan – medical, behavioral, social

- Implementing neurodevelopmental follow-up care for children with congenital heart disease: A scoping review with evidence mapping
BR Abell, K Eagleson, B Auld, S Bora... - ... *Medicine & Child ...*, 2024 - Wiley Online Library
<https://onlinelibrary.wiley.com/doi/full/10.1111/dmcr.15698>
- Health system encounters after loss to cardiology follow-up among patients with congenital heart disease
B Wright, C Fassler, D Tumin, LA Sarno - *The Journal of Pediatrics*, 2024 – Elsevier
<https://www.sciencedirect.com/science/article/pii/S0022347624000349>
- Approaches to Studying Outcomes in Patients With Congenital Heart Disease With Genetic Syndromes: What Down Syndrome Can Teach Us
SM Ware - *Journal of the American Heart Association*, 2024 - Am Heart Assoc
<https://www.ahajournals.org/doi/full/10.1161/JAHA.123.033193>
- Complex Congenital Heart Disease in the Adult
SA Goldstein, RA Krasuski - *Annual Review of Medicine*, 2024 - annualreviews.org
<https://www.annualreviews.org/doi/abs/10.1146/annurev-med-050922-052324>
- Dyslipidemia in adults with congenital heart disease: A systematic review and meta-analysis
W Masson, L Barbagelata, M Lobo... - ... and *Cardiovascular ...*, 2024 - nmcd-journal.com
[https://www.nmcd-journal.com/article/S0939-4753\(23\)00370-8/fulltext](https://www.nmcd-journal.com/article/S0939-4753(23)00370-8/fulltext)
- Health-Related Social Needs, Social Determinants, and Readmissions in Adults With Congenital Heart Disease
KM Kim, RW Walters, MH Kim - *Journal of the American Heart ...*, 2024 - Am Heart Assoc, M Lobo... - ... *Diseases*, 2024 - nmcd-journal.com
<https://www.ahajournals.org/doi/full/10.1161/JAHA.123.032583>

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: www.icbdsr.org

ICBDSR training platform: www.icbdsrtraining.org

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