



Monthly Newsletter

September 2024

Issue 2024 -09

2024 ICBDSR ANNUAL MEETING

The **50th Annual Meeting of the ICBDSR** took place in Prague, Czech Republic, from **September 1 to 4, 2024** at the Hermitage Hotel. The meeting consisted of over 60 attendees, 16 abstract presentations, 17 poster presentations and many guest lecturers.

Special thank you to local organizers Antonin Sipek Jr, Czech Society of Medical Genetics and Genomics, Czech Republic and his team for putting together a successful, enjoyable meeting.



Highlights of the Annual Meeting

Pre-Annual Meeting Workshop (ICBD)



We had a wonderfully active group in the workshop – the afternoon went by in a flash (chocolate may have helped), working through clinical and data quality scenarios, with an ‘intermezzo’ on building informative and beautiful tables.

Now we look forward to workshop participants taking this experience and materials to their home teams and championing the training. A shoutout to Marcia Feldkamp and Cara Mai for helping prepare and run the workshop, and a big thank you to participants for their positive attitude and enthusiasm.

Guest Speakers

Welcome from local hosts

Prof. Ondrej Seda, Chief Medical Genetics Representative, First Faculty of Medicine, Charles University in Prague

The History of the ICBDSR

Pierpaolo Mastriacovo, ICBBD and Simonetta Zezza, Past General Manager ICBDSR

Keynote Lecture – Power of Prevention: CDC’s Story to Unravel a B Vitamin’s Role in Neural Tube Defect Prevention and Strategies to Improve Birth Outcomes

Cara Mai, Division of Birth Defects and Infant Disorders. National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention

J. David Erickson Lecture - A Review of human embryology to improve our understanding of gastroschisis pathogenesis

Marcia Feldkamp, University of Utah School of Medicine

The Annual Business Meeting of the ICBDSR - Tuesday, September 3

With 27 members represented, the Annual Business Meeting covered updates on the Clearinghouse business and the activities of the Executive Committee over the past year. We welcomed two new Affiliate (individual) members – Emma Kalk, School of Public Health, SA and Tidhar Steiner, Semmelweis University Department of Obstetrics and Gynecology, Budapest, Hungary.

The Social Events

Tuesday afternoon Tour of Prague – many delegates chose to participate in the afternoon tour of Prague which included a short tour by bus to the Prague Castle, tour of the Castle, the Charles Bridge and a boat tour along the Vltava river.

That evening, the Social dinner was held at Cafe Louvre, offering a buffet of local cuisine and a chance to relax with the ICBDSR colleagues from around the globe.



Wednesday workshop - Shaping the Future by Reflecting on the Past: 50 Years of Congenital Anomalies

Research

This was a Joint Workshop with the Czech Society of Medical Genetics and Genomics with many local presenters and included a pre-recorded presentation “A personal historical reflection on ICBDSR activities” from R. Brian Lowry, MD -Retired Medical Program Director, Alberta Congenital Anomalies Surveillance System (ACASS) Professor Emeritus, Department of Medical Genetics, University of Calgary, Canada

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.

- **September 02-04 is the 6th Edition of Euro-Global Conference on Pediatrics and Neonatology (EPN 2024).**

The EPN 2024 will be held in Madrid, Spain and will feature a range of keynote speakers, panel discussions, and networking opportunities that are designed to facilitate knowledge sharing and collaboration. The event will be in-person and online. For more information click [here](#).

Meeting website: <https://pediatrics-neonatology-conferences.magnusgroup.org/>

Papers selected by ICBBD

In this issue: congenital heart disease, climate change, world health assembly resolution, and gastroschisis

To find the paper online, click the link embedded in the title or copy the DOI or PMID into 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.

[National population-based estimates for major birth defects, 2016-2020.](#) Stallings EB, Isenburg JL, Rutkowski RE, Kirby RS, Nembhard WN, Sandidge T, Villavicencio S, Nguyen HH, McMahon DM, Nestoridi E, Pabst LJ; National Birth Defects Prevention Network. Birth Defects Res. 2024 Jan;116(1):e2301. doi: 10.1002/bdr2.2301. PMID: 38277408

[Survival of Children With Critical Congenital Heart Defects in the National Birth Defects Prevention Study](#)

Nina E. Forestieri, Andrew F. Olshan, Matthew E. Oster, Elizabeth C. Ailes, Michael P. Fundora, Sarah C. Fisher, Charles Shumate, Paul A. Romitti, Rebecca F. Liberman, Wendy N. Nembhard, Suzan L. Carmichael, Tania A. Desrosiers, The National Birth Defects Prevention Study .

[Population-based prevalence of congenital defects in a routine sentinel site-based surveillance system in the Western](#)

[Cape, South Africa.](#) Emma Kalk, Alexa Heekes, Diane Lavies, Lizel Jacobs, Careni Spencer, Alison Boutall, Ayesha Osman, Chantal Stewart, Mary-Ann Davies, Anika van Niekerk, Karen Fieggen, Andrew Boule, Ushma Mehta Birth Defects Research Volume 116, Issue 8, 08 August 2024

[Genitourinary infection and gastroschisis: A systematic review and meta-analysis](#)

Raya Vinogradov, Annie Muthupunnackal, Malcolm Moffat, Judith Rankin. Birth Defects Research, Volume 116, Issue 7 30 June 2024

[Climate Change and Congenital Anomalies: A Population-Based Study of the Effect of Prolonged Extreme Heat Exposure on the Risk of Neural Tube Defects in France](#)

Tim A. Bruckner, Nhung T. H. Trinh, Nathalie Lelong, Kaveh Madani, Rémy Slama, Joanne Given, Babak Khoshnood Birth Defects Research Volume 116, Issue 9, 2024

[World health assembly resolution for preventing micronutrient deficiencies and associated neural tube defects — A case study of global partnerships for a successful resolution adoption.](#)

Vijaya Kancharla. Birth Defects Research, Volume 116, Issue 6, 2024

[Measuring misclassification and sample bias in passive surveillance systems: Improving prevalence estimates of critical congenital heart defects in state-based passive surveillance systems.](#)

Chris Barnett, James Christiansen, Monica Mills, Jordyn Lord, Jared Parrish. Birth Defects Research, Volume 116, Issue 8. 01 August 2024

WHO alert on Oropouche:

[Oropouche virus disease - Region of the Americas \(who.int\)](#)

[Oropouche virus detected 21 cases in the U.S., CDC says \(statnews.com\)](#)

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

6th Edition of Euro-Global Conference on Pediatrics and Neonatology (EPN 2024)

Sep 26 – 28, 2024

Madrid, Spagna ([map](#))

The EPN 2024 will feature a range of keynote speakers, panel discussions, and networking opportunities that are designed to facilitate knowledge sharing and collaboration. The event will in-person and online.

For more details about the conference: [Click here to visit the conference website](#)

World Spina Bifida and Hydrocephalus Day (WSBHD)

Friday, Oct 25, 2024

The World Spina Bifida and Hydrocephalus Day (WSBHD) has been established and designated by the International Federation for Spina Bifida and Hydrocephalus' (IF) General Meeting in Guatemala in 2011 with the aim of raising awareness and understanding about Spina Bifida and Hydrocephalus(SBH). It also serves as a means to advocate and promote the rights of persons with these conditions. The WSBHD was held for the first time on 25 October 2012 at the European Parliament in Strasbourg. More details: <https://www.worldspinabifidahydrocephalusday.com/>

Website: www.icbdsr.org
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