



Monthly Newsletter

August 2026

Issue 2026 – 08

ICBDSR 2026 Annual Meeting – [LAST CHANCE TO REGISTER!](#)



**52nd Meeting of the International Clearinghouse for Birth Defects Surveillance and Research
Medical Faculty and University Hospital Magdeburg, Germany - September 13 - 16, 2026**

The theme of this year's meeting is:

"Counting What Matters: Data-Driven Advances in Prenatal Diagnosis and Fetal Therapy"

[REGISTER](#) for the Annual Meeting!

[MARITIM Hotel Magdeburg](#) - Reduced rate ends today (August 13)

Book your room early and save! Rooms are available at the rate (**10% off**) for ICBDSR Annual Meeting participants until Thursday 13th August (3 nights). A limited number of rooms are available for Saturday, 12 September, for those attending the pre-conference workshop.

Use code: ABK10MAG

Book your hotel room here: <https://www.ovgu.gmbh/en/veranstaltungen/icbdsr2026/registration>

Last Call: Pre-conference workshop on Sunday, September 13 – Register before August 21

The workshop runs from 1:00–5:00 pm, allowing participants to arrive the day of and transition directly to the opening reception. This hands-on workshop focuses on data visualization and storytelling and builds on the South Africa 2025 workshop. **Attendance is free, but space is limited and advance registration by August 13th is required.** Those who plan to participate are welcome to **email us your goals and top topics** you would like to explore at the workshop. For more information and registration, please visit <https://pretix.eu/ovgugmbh/icbdsr2026/>

Lisi-Hurtado Award

We are pleased to announce Dr. Diana Akhmedzhanova, OMNI-Net Ukraine has been chosen as the 2026 Lisi-Hurtado Award winner. The award will be presented at the upcoming Annual Meeting of the ICBDSR, during which the awardee will present her research on birth defects.

Congratulation to Dr. Akhmedzhanova!

On behalf of the membership, the Executive Committee sends our thoughts and best wishes to our colleagues in Colombia following the recent earthquake.

New Book Written by Dr. R. Brian Lowry: *From Pediatrics to Medical Genetics: An Irish Doctor's Journey*

A chronicle of R. Brian Lowry's long and full life, *From Pediatrics to Medical Genetics: An Irish Doctor's Journey* spans Lowry's experiences in wartime Belfast through his more than six decades devoted to medicine, and his role in the pioneering of medical genetics in Canada.

Lowry's memoir highlights the importance of resilience, cheerfulness, and gratitude—as well as family and sports—and his seminal role in the field of medical genetics in Canada. It is at once a piece of medical history in the fields of pediatrics and genetics, a record of World War II experiences (pre-, during, and post-war), and a memoir for family members and future generations.

Proceeds will be donated by Dr. Lowry to Alberta Children's Hospital Foundation. The book is available for purchase at indigo.ca, [Friesenpress](http://Friesenpress.com), [Amazon](http://Amazon.com), [Barnes & Noble](http://BarnesandNoble.com) and many other locations.

ICBD corner: let's think about joining collaborative studies and publishing our best work

We are taking a short break in August, so this post will be short.

Collaborative studies. A unique strength of a network (any network) is how its value is more than the sum of its parts. This month's **literature corner** highlights some publications from the latest slate of projects (with a couple more submitted or in the final stages). As you know, we are in the planning phase of a **multicenter skeletal dysplasia study** ([click here if interested](#)). But there is plenty of experience, expertise, and data among our programs, so if you have a concrete idea for additional studies, reach out by email or at the Magdeburg meeting.

Rare Diseases and Birth Defects. Many of you have reached out to the editors (Nembhard & Botto) to ask questions and express interest. We look forward to an exciting and forward-looking issue. The call for papers is open, and the link for information is here ([call for papers](#)), including the topics that would best fit with the focus of the issue (the most common question).

Birth Defects and Newborn Screening: WHO Consultation. In case you missed it over the summer holidays, here is a valuable report just issued by the WHO on strengthening capacity for planning and implementing services for these public health priorities. The full report is freely available – [link](#) here

Literature corner (a little different this time)

A tribute to Dr Godfrey Oakley. We are delighted to share the [article](#) by our friend and colleague, Dr. Vijaya Kancharlatter, just published in *Birth Defects Research*, remembering and honoring **Dr. Godfrey Oakley** for his countless contributions to the field. Many of us in the birth defect world knew Godfrey personally. Even those who did not will have encountered his influence and spirit time and time again.

Call for papers still open – Birth Defects Research Special Issue. For more information and list of topics of potential interest, follow this link to the journal: [Call for Papers](#). As a reminder, the issue will focus on what is being done, and what will be done, to leverage the natural interaction of birth defects and rare diseases in ways that bring benefits to both worlds -- enhancing data infrastructure, advancing etiologic research, improving health outcomes, and shaping responsive policies that mitigate the heavy economic, emotional, and social impacts on affected families.

A few ICBDSR collaborative papers published in recent years. As alluded to the 'ICBD Corner', Clearinghouse members have a strong history of collaborative studies that advance science and public health. We present here a few selected ones, published in the last few years, as an invitation to propose more studies we can do together with our rich body of data.

- [Analysis of Prevalence and Mortality Among Neonates and Children With Intestinal Atresia: A Multinational Study, 1974-2015.](#)
- Carreño A, Aguilera MP, Ibañez L, Sarmiento K, Gili JA, Siffel C, Nembhard WN, Bergman JEH, Bermejo-Sánchez E, Tagliabue G, Dastgiri S, Feldkamp ML, Pocius S, Gatt M, Martínez L, Canessa MA, Groisman B,

Källén K, Landau D, Lelong N, Morgan M, Arteaga-Vázquez J, Santoroi M, Rissmann A, Sipek A, Szabova E, Wertelecki W, Canfield MA, Mastroiacovo P, Zarante I. *Birth Defects Res.* 2026 Apr;118(4):e70032. doi: 10.1002/bdr2.70032.PMID: 42007667

- [Analysis of early neonatal case fatality rate among newborns with congenital hydrocephalus, a 2000-2014 multi-country registry-based study.](#)
- Gili JA, López-Camelo JS, Nembhard WN, Bakker M, de Walle HEK, Stallings EB, Kancherla V; ECEMC Peripheral Group; Contiero P, Dastgiri S, Feldkamp ML, Nance A, Gatt M, Martínez L, Canessa MA, Groisman B, Hurtado-Villa P, Källén K, Landau D, Lelong N, Morgan M, Arteaga-Vázquez J, Pierini A, Rissmann A, Sipek A, Szabova E, Wertelecki W, Zarante I, Canfield MA, Mastroiacovo P. *Birth Defects Res.* 2022 Jul 15;114(12):631-644. doi: 10.1002/bdr2.2045. Epub 2022 May 28.PMID: 35633200
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- [Prevalence and mortality among children with anorectal malformation: A multi-country analysis.](#) Kancherla V, Sundar M, Tandaki L, Lux A, Bakker MK, Bergman JE, Bermejo-Sánchez E, Canfield MA, Dastgiri S, Feldkamp ML, Gatt M, Groisman B, Hurtado-Villa P, Kallen K, Landau D, Lelong N, Lopez-Camelo J, Martinez LE, Mastroiacovo P, Morgan M, Mutchinick OM, Nance AE, Nembhard WN, Pierini A, Sipek A, Stallings EB, Szabova E, Tagliabue G, Wertelecki W, Zarante I, Rissmann A. *Birth Defects Res.* 2023 Feb 1;115(3):390-404. doi: 10.1002/bdr2.2129. Epub 2022 Nov 19.PMID: 36401554
- [Gastroschisis prevalence patterns in 27 surveillance programs from 24 countries, International Clearinghouse for Birth Defects Surveillance and Research, 1980-2017.](#)
- Feldkamp ML, Canfield MA, Krikov S, Prieto-Merino D, Šípek A Jr, LeLong N, Amar E, Rissmann A, Csaky-Szunyogh M, Tagliabue G, Pierini A, Gatt M, Bergman JEH, Szabova E, Bermejo-Sánchez E, Tucker D, Dastgiri S, Bidondo MP, Canessa A, Zarante I, Hurtado-Villa P, Martinez L, Mutchinick OM, Camelo JL, Benavides-Lara A, Thomas MA, Liu S, Nembhard WN, Gray EB, Nance AE, Mastroiacovo P, Botto LD. *Birth Defects Res.* 2024 Feb;116(2):e2306. doi: 10.1002/bdr2.2306.PMID: 38411327
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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)

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