International Clearinghouse for Birth Defects
Surveillance and Research

Monthly Newsletter

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ICBDSR 2026 Annual Meeting – REGISTER TODAY!

52nd Meeting of 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
Book your room early and save! Rooms are available at the rate (10% off) for ICBDSR Annual Meeting participants to **Thursday 13th August** (3 nights) and 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

Pre conference workshop on Sunday, September 13

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 in at the workshop. For more information and registration, please visit https://pretix.eu/ovgugmbh/icbdsr2026/

Post conference tour on Thursday, September 17 - Trip to Quedlinburg

While in Germany, why not add the post conference tour to your registration for a chance to visit this world heritage site? Be sure to register and book the tour by **August 13th** in order to save your spot. For more information and registration, please visit https://pretix.eu/ovgugmbh/icbdsr2026/

ICBDSR Birth Defect Report: data submission notes

Past deadline: May 31, 2026

We appreciate the programs that have completed the data submission. As program leaders and Clearinghouse members, accurate and timely data sharing is a shared responsibility. The upcoming 2026 report (data submitted 2025) will be the abbreviated report, and the 2027 report (data submitted 2026) will be a comprehensive report.

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, Amazon, Barnes & Noble and many other locations.

ICBD corner: studies and publication opportunities (and holidays)

The multicenter skeletal dysplasia study. Several program leaders have expressed interest in participating in this study. As conditions that span the worlds of congenital anomalies and rare disorders, skeletal dysplasias — more than 450 heritable bone disorders — help highlight the challenges of data gaps, ascertainment, coding, and data harmonization. As a consequence, with the potential exception of achondroplasia, reliable prevalence estimates and outcome data are scarce or entirely lacking. **Participation is still open** (complete the survey if interested click here for form) for a limited time. A first set of communications will be sent by email, and we look forward to discussion in and around the annual meeting.

The call for papers from Birth Defects Research. As noted in the June newsletter, this special issue seeks to stimulate new thinking and dialogue by highlighting current and emerging approaches, persistent gaps, and future directions in surveillance, research, community engagement, and policy at the intersection of birth defects and rare diseases. *Read more about this opportunity below, in this issue's Literature Review.*

Lastly, ICBD will be taking time off in August for the summer holidays, with limited email access. If urgent, please say so in the email subject. See you all in September.

Literature corner: a call for papers

The Intersection of Birth Defects & Rare Diseases: A Public Health & Clinical Imperative

Birth Defects Research Journal Special Issue
Initial Submission deadline: November 30, 2026

While birth defects and rare diseases are distinct categories, their substantial clinical and public health overlap offers a critical opportunity for aligned collaboration. This special issue aims to foster new dialogue and innovative strategies—such as integrating rare disease and birth defects surveillance systems—to enhance data infrastructure, advance etiologic research, improve health outcomes, and shape responsive policies that mitigate the heavy economic, emotional, and social impacts on affected families.

For more information and list of topics of potential interest, follow this link to the journal: **Call for Papers**

17th International Skeletal Dysplasia Society Meeting

Toronto, Ontario, Canada | August 26–29, 2026
For more information, please visit: https://www.isds.ch/index.php?page=isds-2026-meeting

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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